State of Utah MCH Block Grant Needs Assessment
FFY2005 – FFY 2010

I. Needs Assessment Process

The initial planning process for the FY2005-2010 needs assessment process included a review of the FY2000 process to determine its effectiveness in identifying needs for mothers and children in the state from a broad perspective. The review led us to realize that we needed to seek broader input on the needs of pregnant women, mothers, young children, adolescents and children and youth with special health care needs than we had obtained for the previous needs assessment. In our discussions, we decided to ensure that we had input from individuals representing a broader view of health needs and issues for mothers and children in the state, including parents, parents of children and youth with special needs, members from all advisory committees that relate to MCH or CYSHCN issues, as well as other stakeholders working with mothers and children in the state.

The lead staff in the Division of Community and Family Health Services developed a plan for the five-year needs assessment that included development of a survey for each of the MCH populations and health service or system issues, involvement of the MCH/CSHCN Advisory Committee and its separate subcommittees, review of the recommended priority areas identified by each of the subcommittees to determine the final priorities for the Title V efforts for FY2006-2010. Key staff in the Division also participated in an abbreviated CAST – 5 process to identify areas in which the agency needs to develop additional capacity.

Division staff developed a key informant survey to solicit opinions on key health issues in four areas: mothers and infants; young children and adolescents; children and youth with special health care needs; and, health care services. Various staff and outside partners were included in the development of the survey to ensure that it reflected key issues for each of the MCH populations. Members of the State ICC were involved in the key informant survey to ensure that they had an opportunity to voice their concerns regarding children and youth with special needs. The survey was designed for online response, however, hard copies of the survey were sent to individuals for whom we had no email address. With the request for survey participation, we encouraged those we contacted to forward the survey information to anyone they thought might be interested in providing input so that we could obtain as many responses as possible. Numerous individuals in the state representing various components of the system, such as local health departments, community health centers, the Department's Ethnic Health Advisory Committee, private providers, advocacy organizations, parents of children and youth with special health care needs, agencies working with mothers and children, various Department advisory committees that address issues relating to the three MCH populations, etc. were contacted to participate in the survey.

Division data staff tabulated the survey responses and sorted the issues by rank order in each of the categories mothers and infants; children and youth; children and youth with special needs, and health care service. Almost 700 individuals (694) were contacted directly to participate in the survey, with 411 responses returned for a response rate of 59% (based on the number directly contacted). The respondents may include others we did not directly contact since we had encouraged wide distribution of the survey. Of the responses received, 83% were online responses. Interestingly, the largest group of responders was parents comprising 22% of the responders, with local health department staff comprising the next largest group at 17%.

The top five issues identified by survey respondents are as follows:

<u>Health Issues for Mothers and Newborn Babies</u>

Unplanned pregnancies

Obesity
Depression or other mental health problems
Closely spaced pregnancies
Poor nutrition during pregnancy

Health Issues for Children and Adolescents
Lack of physical activity
Obesity
After school supervision
Teen pregnancy
Depression or other mental health problems

Health Issues for Children and Youth with Special Health Care Needs
Lack of physical activity
Lack of respite care
Depression or other mental health problems
Transition to adult life and self-sufficiency
Lack of child care

Health Care Services Issues
Dental insurance
Obtaining financial help for health care
Health insurance
Services not covered by insurance
Dental care

These results were presented to the members of the MCH/CSHCN Advisory Committee in a February meeting for their review. MCH/CSHCN Advisory Committee and subcommittee membership includes broad representation from local health departments, community health centers, the dental and medical provider community, nursing, Head Start, Child Care Licensing, Medicaid, Utah CHIP, the Utah Statewide Immunization Information System, Planned Parenthood Association of Utah, Family Voices, etc. as well as staff from other Department programs. The MCH/CSHCN Advisory Committee is comprised of three subcommittees, one for each of the three MCH populations. After the MCH/CSHCN Advisory Committee meeting, subcommittees met separately to discuss the survey results in more detail and after review of additional data, determined two to three priorities they recommended be addressed in the next five years.

State MCH/CSHCN Priorities for FFY2006-FFY2010

The MCH Advisory Committee met to review and comment on the proposed priorities and state performance and outcome measures. The following are the top five issues identified by the subcommittees after review of the key informant survey results and review of other issues and related data as identified by each of the subcommittees.

Mothers and Infants
Overweight and obesity in pregnancy
Underweight in pregnancy

Inadequate/excessive weight gain during pregnancy
Intended pregnancies
Short interpregnancy spacing (less than 18 months since previous live birth
Postpartum depression
Women between 18-25 years without insurance

Children and Youth

Obesity prevention (including nutrition, physical activity, and Type II Diabetes prevention)
Asthma prevention
Mental health promotion and primary prevention (including screening and referral for depression and suicide)
Cigarette smoking prevention
Oral health promotion

Children and Youth with Special Health Care Needs

Funding (all inclusive)
Medical Home
Transition/vocational Rehabilitation
Rural Health
Ethnic/Cultural

Identification of the State Priorities:

Key Title V staff, including the Division's family advocate, reviewed the results of the survey to identify potential priorities and state performance and outcome measures

1. Depression and mental health (mothers, children)
2. Obesity (women [pre-pregnant and weight gain in pregnancy], children)
3. Intendedness of pregnancy (includes short interpregnancy spacing)
4. Medical home (all)
5. Access to health care for women of childbearing ages and children
    a. Women of childbearing ages who do not have insurance
    b. Rural health
6. Oral health (all)
7. Transition and vocational rehabilitation (CSHCN)
8. Ethnic/cultural
9. Genomics

State Performance Measures FY06-FY10

Key Title V staff, including the Division's family advocate developed state performance measures related to the new state priorities. We retained three of the previous state Performance Measures and developed six new Performance Measures to reflect the State Priorities. We decided not to develop State Performance Measures for ethnic/cultural or genomics as we want to work with those areas more to determine if we can develop an appropriate State Performance Measure. New performance measures are indicated with (N) in front of them:

(N) Percent of women of reproductive age (18-44) who is uninsured

Proportion of pregnancies that result in a live birth that are intended

(N) Percent of women with normal pre-pregnancy weight who deliver a live born infant

(N) Percent of women with appropriate pregnancy weight gain who deliver a live born infant

(N) Proportion of women who deliver a live born infant reporting moderate to severe depression who seek help from a doctor or other health care worker

(N) Percent of children who are at-risk for overweight and overweight

(N) Percent of youth during the last 12 months who feel so sad or hopeless almost every day for two weeks or more in a row that they stopped doing usual activities.

Percent of children six through nine years of age enrolled in Medicaid receiving a dental visit in the past year.

Percent of children with special health care needs in the rural areas of the state receiving direct clinical services through the state CSHCN programs.

Key Title V staff participated in an abbreviated version of CAST-5 to evaluate the state Title V agency's capacity. The Title V Director, MCH and CSHCN Bureau Directors along with other key staff reviewed the elements of CAST-5 to assess the Utah Title V agency's capacity needs. Overall the review indicates that Utah's Title V agency has much capacity and the elements that were noted as needing improvement really only reflect the desire to development these elements to a higher level. The elements are in place, but barriers may prevent staff from accomplishing as much as they would like. Overall, the agency has capacity for 21 of the 28 elements, with the remaining 7 elements needing improvement or further development. The seven elements included:

- Authority and funding sufficient for functioning at the desired level of performance – the challenges in this element include: inability to create new positions to address capacity needs due to legislative restrictions; restrictions on applying for grant funds if new positions are needed to carryout the grant; and limited state funds for grants that require non-federal match.

- Mechanisms for accountability and quality improvement – we have informal processes in place for quality improvement for many programs, but limited ability to implement quality improvement with contractors, such as local health departments. Programs providing direct services tend not to be receptive to quality improvement as it interferes with service provision.

- Formal protocols and guidance for all aspects of assessment, planning and evaluation cycle – this element is one that we need to focus more on and develop staff capacity.

- Adequate data infrastructure – We have strong data support, but capacity needs to be built to better support data needs of the state Title V agency in its work, especially related to ethnic and minority population data.

- Other relevant state agencies – While the UDOH has strong collaborative relationships with many state agencies, the State Office of Education has been very difficult to engage in collaborative initiatives. With a new Executive Director, perhaps this will change for the better.

- Businesses – this is an area that the Division of Community and Family Health has embarked on to a certain degree, but needs further development.

- Ability to influence policy-making process – The Department has the ability to influence policymakers to the degree that is within the boundaries of state government roles and the Governor's agenda. The new Executive Director of the Department of Health has vast experience in government nationally which will greatly benefit public health and Title V in the state as he works to overcome challenges we face.

In addition to these processes that were developed specifically for the five year needs assessment process, the MCH Bureau sponsored meetings in 2004 with members of the State Perinatal Taskforce to identify four priorities to work on over the next year or so. Of all the issues included in the evaluation, four priority areas emerged:

Family planning
Low birth weight and prematurity
Barriers to prenatal care
Depression and other mental health issues

These four priorities correspond to the issues identified through the key informant survey. Members of the Taskforce have signed up for one of the four subcommittees to address each of the priorities. The subcommittees are developing strategies to address each of the priority areas.

The needs assessment process also included a review of status on National and State Performance and Outcome Measures, as well as Health Status, Health Systems Indicators and health care systems in the state. This review assisted in identifying priority areas along with the top issues obtained from the key informant survey. The needs assessment process also included a review of status on National and State Performance and Outcome Measures, as well as Health Status, Health Systems Indicators and health care systems in the state. This review assisted in identifying priority areas along with the top issues obtained from the key informant survey. The state accomplished 11 National Performance Measures. The Measures that we did not accomplish included several that we had made progress on, but the indicator was slightly lower than the objective. The areas that we did not achieve included: up-to-date immunizations for children, deaths of children due to motor vehicle accidents and youth suicides, uninsured children, low birth weight, very low birth weight infants born in tertiary centers, and entry into prenatal care. The measures for immunizations and uninsured children are 2004 data, however, the vital records data are provisional, which may impact the number of National Performance Measures obtained. State Performance Measures were all noted as accomplished, however, as with the National Performance Measures, some are reported with provisional data, so this too may change what was accomplished or not.

For quantitative methods, staff reviewed demographic data, health system capacity data to identify gaps and health issues that were becoming increasingly concerning, such as asthma hospitalizations for young children; the disparity among Medicaid mothers related to entry into care, adequacy of care, low birth weight and infant deaths compared to non-Medicaid mothers; and, the low percent of Medicaid enrolled children who received dental services. Data capacity is strong in the Utah Department of health and has progressed to almost full capacity over the last several years.

In addition, throughout the year, staff attended numerous meetings from which they gained input from a variety of individuals in the state on needs of mothers and children in Utah. The problems discussed in many of these meetings reinforced the identification of key issues, but also provided additional information that was factored into the identification of state priorities.

This year's needs assessment effort has produced invaluable information about the needs of Utah mothers, infants, children, adolescents and children with special health care needs, including adolescents with special health care needs that the Division and others will be able to utilize in planning improved services and programs to better address the populations served through these funds. Recognizing that the needs assessment is an ongoing process, Title V leadership will continue to monitor Utah's progress in the priority areas identified in the needs assessment process, including those that were not included in the final list. Each year as additional data become available, such as adequacy of prenatal care statistics, programs review the data and seek strategies to address the findings.

This input from a variety of partners, especially families, has been very helpful in guiding discussions among the three subcommittees of the MCH/CSHCN Advisory Committee to identify the state top priorities or unmet needs of Utah's mothers and children. The overall needs assessment process has afforded the sate Title V agency, its staff and its partners to examine the current status of health of the state's population and the health system needs.

II. Needs Assessment Partnership Building and Collaboration

The state Title V agency has strong partnerships with other HRSA-funded programs, such as Primary Care and HIV/AIDS, other programs in the Department, such as health promotion, Medicaid, CHIP, vital records and health statistics (known in Utah as the Center for Health Data, Office of Vital Records and Statistics, Office of Health Statistics), injury prevention and control, immunizations, etc. The Division of Community and Family Health Services includes the major health promotion programs of the Department, including violence and injury prevention and control; and the Immunization and WIC programs are housed in the MCH Bureau of the Division. The Division has a very strong and collaborative relationship with the state Medicaid agency, a sister Division in the Department. Division staff frequently works with Medicaid and/or CHIP (Utah's CHIP Program, while separate from Medicaid, is administered by Medicaid) on projects or initiatives of mutual interest and commitment. Medicaid in Utah has demonstrated a clear commitment to children in the state and has been involved in several grant opportunities related to children's health, such as the ABCD I and II projects. Title V staff has worked very effectively with Medicaid on these projects. The Center for Health Data includes vital records, hospital discharge data, surveillance capacity and so on. The Center is a leader in the nation related to data linkages, online data systems, such as IBIS. Title V staff participate in meetings with the Center for Health Data staff and Title V staff invite Center for Health Data staff to participate in Title V efforts, such as the Perinatal Task Force, the MCH/CSHCN Advisory Committee and so on.

The state Title V agency works well with the state Primary Care Organization and Association. Through efforts of the State Dental Director, the state loan repayment program was expanded to include dentists in an effort to attract dentists to the rural areas of the state. Division staff has developed a stronger relationship with the State Primary Care Association, State Primary Care Organization and the community health centers by invitations to sit on Division advisory committees, etc. CFHS has established a partnership with the Bureau of Communicable Diseases on issues related to STDs, HIV/AIDS, and teen pregnancy prevention. The Bureau of Communicable Disease is in a sister division of the state, thus collaboration is important in moving forward on areas that impact women of reproductive age and youth.

Relationships with other state and private agencies are strong and broad-based. Much of the work that Title V is engaged in involves collaboration with key partners, so this is a real strength of Utah's Title V agency. The role that key partners played in the needs assessment included: participation on the MCH/CSHCN Advisory Committee and its subcommittees, participation in the Key Informant Survey which was a component of the Utah Needs Assessment process, and information obtained in numerous meetings, both internal and external to the Title V agency, provided information to be included in the needs assessment. The Key Informant survey was widely distributed to members of Department advisory committees, local health departments and local agencies, partner agencies, and parents.

The strength of the state collaborative efforts are that we have engaged many more partners during the past five years than previously, especially the private provider community, the University of Utah Department of Pediatrics, Department of Obstetrics and Gynecology and the Department of Family and Community Medicine as well as health care professional organizations, in our work. We now have a stronger relationship with the mental health community than in the past – we are at the table of discussions around building the infrastructure for children's mental health, a major advance in relationships since mental health is under the purview of another Department. There is always room for improvement and we will continue to review key partnerships and work to establish new or stronger relationships with additional partners needed for us to fulfill the work of healthy mothers and children. The weakness of the state collaborative efforts is that we have not effectively engaged parents (with exception of parents of children with special health care needs) in our work, nor have we effectively engaged businesses. The collaborative efforts of the Utah Title V agency have been extensive, and often we meet key players in multiple meetings. Collaborative efforts take time, involve more effort, but are extremely worthwhile for producing a finer work product or service than if done without the input of key partners. For Utah, this is a real strength. In summary, partners played a key role in helping us identify new state priorities on which to focus over the next five years.

III. Overview of the Maternal and Child Health Population's Health Status

Introduction

Utah's population estimate for 2003 was 2,351,467, which represents a 5.3% increase over the 2000 Census numbers. Utah has the highest birth and fertility rates in the nation. Utah continues to have the youngest population in the nation with a median age of 27.7 years. The American Community Survey Summary indicated that 32% of the Utah population was under the age of 18 years in 2003.

Utah is largely a rural and frontier state, with the majority of the state's population residing along the Wasatch Front, a 75-mile strip running from Ogden (north) to Provo (south) with Salt Lake City, the state's Capitol, in between. The Wasatch Front comprises only 4% of the state's landmass, but 76% of the state's population resides here. The rest of the population (24%) resides in the remaining 94% of the state's land mass comprised of rural areas of more than six, but less than 100 persons per square mile and frontier areas of less than six persons per square mile. Five percent of the state's population lives in the frontier area (70% of the land mass), and 19% lives in the rural portion (26% of the land mass). The geographic distribution of the state's population presents significant challenges for accessing health care services for those living in the rural and frontier areas as well as for delivery of health care services. In the rural and frontier areas, many residents are not able to readily access health care services due to long travel distances and lack of nearby hospital facilities and health care providers, especially specialists. Specialists are not available to rural/frontier residents except by traveling hundreds of miles. In addition residents living in the rural/frontier areas may be reluctant if not unwilling to utilize certain services, such as family planning, mental health, because of concern for confidentiality and anonymity in seeking these services in a very small town.

While Utah continues to be predominately white, ethnic minorities now make up a larger portion of the state's population. In 2003, Hispanics accounted for 10% of state's total population, a 15.8% increase since 2000. Refugee populations in Utah are growing, along with the Hispanic populations, with resultant increasing need for language translation services. These factors impact the health care system's ability to adequately address the needs of the diverse populations.

Of particular concern in meeting health care needs of Hispanics is the increasing number without documentation. These families are more difficult to reach due to language barriers; cultural beliefs about preventive health care; transportation constraints; and ineligibility for many government programs. Prenatal care for women without documentation is a problem since they are not eligible for public assistance, even though their newborns will be citizens and eligible for benefits. U.S. Citizenship and Immigration Services (formerly INS) has raided businesses with a large undocumented worker population resulting in deportation of these workers creating an environment of fear and distrust of government agencies.

The Department of Health, with funding from the 2004 and 2005 Legislature, has created a Center for Multicultural Health that is charged with addressing the needs of minority and ethnic populations in the state. The Center has worked to inventory Department program gaps in addressing health needs for ethnic and minority populations and to develop strategies to address these. The Center staff has also worked with the Office of Public Health Assessment to update a Department's report on needs of minority and ethnic people in Utah.

Based on the Utah Health Status Survey (UHSS), 10.2% of Utah's population reported no health insurance in 2004, a steady increase from 8.7% in 2001. The proportion of uninsured has increased in the maternal and child populations as well. In 2004, 8.2% of children under age 18 were uninsured compared to 6.8% in 2001. Of females ages 18-49, 13.9% reported no health insurance in 2003 compared to 10.8% in 2001. More than a quarter (25.8%) of the Hispanic population reported no insurance in the 2001 UHSS, the only year the data were available. The steadily climbing rates of uninsured individuals in the state especially children and women of childbearing ages, is very concerning. The Governor recently sponsored a state summit to discuss issues related to a state plan to address the increasing rates.

Services for the three populations served through Title V are offered in a variety of settings: private provider offices; public providers in local health departments, community health centers, a

clinic for the homeless, and migrant health clinics; privately run free clinics; itinerant clinics offered through the CSHCN Bureau to rural communities without specialty providers; and, specialty settings, such as the University of Utah Health Sciences Center, Primary Children's Medical Center, and Shriners Hospital for Children.

The Medicaid income eligibility levels for programs for children and pregnant women have not increased since established in 1990. Medicaid's current eligibility level for children birth -5 years of age is 133% FPL and 100% FPL for children 6-18 years of age. The Utah CHIP eligibility level is 200% FPL for children from birth to age 18 years.

Since 1995 Medicaid participants living in Utah's urban counties have been required to enroll in a managed health plan. This requirement is the Choice of Health Care Delivery Program, which is allowed under a federally approved freedom-of-choice waiver. As recently as 2002, the Utah Department of Health's Division of Health Care Financing (HCF), Utah's Medicaid agency, contracted with four different managed health plans to provide services to Medicaid participants in Utah's urban counties. Since then health plans have struggled financially to continue delivering services to the Medicaid population. Currently, Medicaid has contracts with three health plans to deliver services to enrollees in Utah's four urban counties, including children with special health care needs. Two of these plans are managed care plans; the third is a preferred provider network. One health plan continues to expand into rural areas of the state providing an option for Medicaid participants in most areas of the state. At the present time enrollment for rural Medicaid participants is voluntary, allowing them the option of choosing either fee-for-service, a primary care provider or a health plan if available. Medicaid participants in all but three rural counties are enrolled in a Prepaid Mental Health Plan for behavioral health services.

The Utah Department of Health's Division of Health Care Financing believes that since mandatory health plan enrollment began in 1995, health plans have at the forefront of their organizations a commitment to continuous quality improvement as well as providing the most cost effective care. This commitment has resulted in each plan conducting numerous quality improvement initiatives to improve areas like access, disease management, processes of care, health outcomes, and service quality. Managed care plans have also provided a level of case management and care coordination heretofore ineffective or absent in the fee-for-service environment in any comparable fashion. At this time, the availability and delivery of health care through the health plans in the rural areas of the state is too new to make a determination of its impact on services for the maternal and child populations.

As of July 1, 2004, Medicaid participants living in Utah's urban counties must stay with the same health plan for 12 months, which should facilitate the ability of the health plans to track participant services, outcomes, etc. Since 1996, HCF has required that managed care plans meet the federal EPSDT requirements in the HCFA-416 report for data specific to EPSDT screening. HCF calculates plan-specific participation rates using these data. Since 1996, managed care plans are required to report all efforts (through quality monitoring reviews) to track prenatal care, family planning, EPSDT and immunizations through their internal improvement initiatives and auditing as well as through HEDIS reporting. As of March 1, 2005, the Medicaid Managed Care System is operational for accepting and processing encounter data. In addition, there are two immunization incentive clauses in the contracts based on managed care plans' HEDIS scores for immunizations for two year-olds and adolescents. Studies continue to assess the full impact that managed care is having on the Medicaid population in the state.

Utah, not unlike other areas of the country, suffers from a shortage of certain types of health care providers in different geographic areas, including nurses, neonatologists, dentists, mental health

professionals, etc. Provider shortages exist throughout the state. The Health Professional Shortage Area (HPSA) maps detail areas of the state with provider shortages for medical, dental and mental health providers. Access to dentists in Utah is a major issue, particularly for Medicaid participants and for individuals living in rural/frontier areas of the state.

Demographics of the State

Utah is the fifth fastest growing state in the nation. Utah's population estimate for 2003 was 2,351,467, a 5.3% increase from the 2000 Census compared to 3.3% for the nation. Utah experienced a 29.6% population increase from the 1990 to the 2000 Census. According to the Governor's Office of Planning and Budget estimates, by the year 2010, Utah's population will grow to 2.8 million.

In 2003, the population of every racial and ethnic group, except White (both Hispanic and non-Hispanic), grew at a higher rate than the state. During 2000 to 2003, among the five race categories, the highest growth rate occurred among the Black population (16.6%), followed by Asian (15.5%), Native Hawaiian and Pacific Islander (10.1%), American Indian/Alaskan Native (7.2%), and White (4.9%). Ethnic and racial minorities make up 15.7% of Utah's total population. Between 2000 and 2003, the Hispanic population in the state had grown by 15.8%, accounting for 10% of state's total population compared to 14% nationally. The following table shows the racial and ethnic make-up of Utah's population based on the 2003 Population Estimates Program (PEP) U.S. Census Bureau:

Race/Ethnicity	Proportion	Race/Ethnicity	Proportion
White, non-Hispanic	84.3%	Asian	1.9%
Hispanic	9.9%	Native Hawaiian/Pacific Islander	0.7%
Black	1.0%	Two or more races	1.3%
Native American	1.4%		

Five major tribes have inhabited and continue to inhabit Utah: 1) Ute; 2) Dine' (Navajo); 3) Piute; 4) Goshute; and 5) Shoshone. All five tribes have managed not only to survive, but progress despite their difficult past.

Culture, religion and policy – Utah's predominant religion counsels against the use of tobacco and alcohol and consequently results in a lower incidence of diseases associated with abuse of these substances, such as liver disease, alcoholism, and lung cancer. Utahns pride themselves on family values and support many efforts to improve maternal and child health. The political environment is conservative with a fairly large group of individuals who hold anti-government philosophies that at times make it difficult to obtain state funding for state agency programs.

Children in Utah - Utah's child population is unique in that it is proportionally larger than the rest of the nation. In 2003, 49,834 babies were born. In 2003 Utah's birth rate was the highest in the nation at 50% above the national rate, 21.2 per 1,000 births compared to 14.1 nationally. The following table includes data from the 2003 American Community Survey Summary:

U.S. Population Distribution by Age		Utah Population Distribution by Age	
Age	Percent	Age	Percent
17 and under	25.7%	17 and under	32.0%
18-24	9.1%	18-24	12.8%
25+	65.2%	25+	55.3%

Family structure and household size – For many years Utahns have had larger households compared to the nation. In 2003, Utah's household size was 3.07 compared to the national average of 2.61. Utah's average family size was 3.55 compared to the national average of 3.19. The percent of Utah family households with children is 30% higher than the rest of the nation, 42.0% versus 32.2%. Utah Hispanic households comprise 7.1% compared to 10.0% in the U.S. However, Utah Hispanic household size was much larger than the U.S. (3.9 vs. 3.5) Households comprised of single mothers with children are lower in Utah than the nation, (5.7% vs. 7.6%).

Income – Utah's median household income was somewhat higher than that of the U.S. However, Utah's households are also larger with a significantly lower per capita income in Utah than in the U.S. overall. Based on the 2003 American Community Survey Summary, Utah's median household income of $52,481 was slightly higher than the U.S. average of $52,273, ranking Utah 15th nationwide. Due to larger families in Utah, the per capita income ranked the state 45th in the nation at $18,905.

Domestic Violence/Abuse and Neglect – In 2003 there were 5,846 domestic violence cases in Utah District Courts which represent protective order filings. In fiscal year 2004, the Division of Child and Family Services handled 12,579 victims of abuse and neglect, a rate of 14.8 per 1,000 children. Of those, 15% (1,894) were removed from the home. Over 1,000 of children were removed from home due to parental drug abuse and inadequate parenting skills. Over 500 cases involved family violence.

In fiscal year 2004, more than 20,000 (20,936) of children served by child protective services were placed into the foster care system, a 19.8% increase in cases since fiscal year 2001.

Juvenile crime - In 2003 the rate of juvenile (children aged 17 or younger) crime arrests was 8,830 per 100,000 children age 10 to 17, representing a decrease from the 2000 rate of 9,854 per 100,000.

Poverty – The 2003 Utah Health Status Survey has estimated that 8.2% of Utahns are living at 100% of the federal poverty level (FPL). For children under 19, 10% are living at this poverty level.

Participation in Selected Department of Workforce Services Programs –

Program	October 2003	October 2004
Number of Food Stamp cases	47,347	52,500
Number of FEP cases	6,558	6,475
Children receiving Family Employment Program child care benefits		
Regulated Care	1,232	1,226
Unregulated Care	1,210	1,182
Children receiving employment support child care benefits		
Regulated Care	5,172	5,762
Unregulated Care	3,914	4,156

Labor Force – Based on the U.S. Census, a total of 126,183 Utah children under age six and 411,780 children under age 18 had both parents or an only parent in the labor force. Of all children under age six, the proportion that has both parents or an only parent in the labor force is somewhat higher in the U.S., 58.6% in U.S. compared with 52.3% in Utah. Among women aged 16 or older with children under age six, 6% (48,648) are in the labor force in Utah compared with 4.8% in the U.S. Utah's unemployment rate has been lower than the national rate for the last three years. The national rate dropped from 6.0% in 2003 to 5.5% in 2004 while Utah's rate declined from 5.7% to 5.2% over the same time period. Currently, as of May 2005, the seasonally adjusted unemployment rate is 4.9%. Utah appears to be following the national trend of a declining rate.

Education - Based on the 2003 American Community Survey, Utah had a significantly higher percentage of high school graduates at 90% versus 84% nationally among individuals 25 years and older with a high school diploma. Utah's population is similar to the national population for percent of the population with a bachelor's degree or higher degree (26.2% in Utah compared to 26.5% of the U.S. population). Even though the proportion of Bachelor's degree and higher education achievement was comparable, Utah has a higher percentage of individuals with some college but no degree at 29% compared to 20% nationally. The high school drop out rate in Utah is not as high as the U.S. at 6% of youth ages 16 to 19 years old versus 8% at the national level.

Schools - The National Center for Education Statistics identified Utah as the lowest in the nation for funding per elementary and secondary student during 2001 to 2002 at $4,900. The national average was $7,734 per student with the District of Columbia spending the most at $12,102 per student.

For the 2003-2004 school year the pupil/teacher ratios for elementary school children were 24.4 and for grades 7-12 the ratio was 24.0.

The Free and Reduced Lunch Program is available to Utah school children. If the family is at 130% of FPL or less, their children are eligible for a free lunch and a reduced lunch if between 131-185% of FPL. In 2003 34.2% of Utah school children utilized the program. The participation rate does not reflect all eligible children since not all necessarily apply for the program.

Head Start - The total number of children and pregnant women enrolled in Utah Early Head Start and Head Start for 2003-2004 was 7,313. More than 6,800 (6,880) families used Head Start services, of which 60.3% were two parent families and 39.8% were single parent families. Head Start enrolls children ages 3 to 5 at 100% of FPL. Based on poverty estimates from the 2003 Utah Health Status Survey about 39.5% of eligible children were enrolled in Head Start.

Selected economic indicators of Head Start families include:

Family Assistance among Head Start Families	Number	Percent
Families receiving any cash benefits or other services under the TANF (FEP) program	1,544	22.7%
Families receiving Supplemental Security Income	296	4.4%
Families receiving WIC services	3,357	49.4%
Homeless families served during the enrollment year	239	3.5%
Homeless families who acquired housing during the enrollment year	176	73.6%

Services received by Head Start families included:

Service Received	Number
Parenting education	2,778
Health education (including prenatal education)	2,147
Emergency/crisis intervention (addressing immediate need for food, clothing or shelter)	1,427
Housing assistance (subsidies, utilities, repairs)	1,290
Adult education (GED programs, college selection)	867
ESL training	619
Mental health services	542
Job training	384
Substance abuse prevention or treatment	356
Transportation assistance	323
Child support assistance	318
Child abuse and neglect services	269
Marriage education services	210
Domestic violence services	147
Assistance to families of incarcerated individuals	106

Public Health Program Utilization - Low-income status has a major impact on the health of women and children. In 2003 Medicaid paid for 31.6% of all Utah deliveries. Approximately 40% of women who delivered in Utah in 2003 were enrolled in WIC services and 48.1% of infants born in the state were enrolled in WIC.

More than 90% (92.2%) of potentially Medicaid eligible children (1 - 18 years) were enrolled in Medicaid in 2003. In Utah, the state CHIP Program covers children up to 200% of the FPL. The 2003 Utah Health Status Survey estimated that 40% of children under 19 were from families at 200% of FPL. The largest proportion of children at or below 200% FPL falls between 101-200% FPL. Using the monthly average enrollment for CHIP during 2003 it appears that about 59 % of children below 200% FPL were enrolled. Based on Medicaid and CHIP enrollment it is estimated that only 61% of potentially children living at 200% FPL are covered by these two

programs. A large number of the children not enrolled in Medicaid or CHIP may have been eligible for the CHIP Program but the program's enrollment was capped up to June 30, 2005. With increased enrollment capacity, the percentage of children enrolled in CHIP should increase.

Another program that promotes the health of young children in poverty is WIC. Utah has estimated that only 78.1% of children under 5 years old at 185% FPL are enrolled in the WIC program. Public assistance programs such as TANF provide help to families in poverty. Based on 2003 data provided by the Office of Family Assistance at Department of Health and Human Services, 8,745 Utah families were enrolled in TANF, representing 1.6% of all families in the state.

Access to Care – In 2003 more than 420,000 Utahns were unable to get needed medical, dental or mental health care in the previous 12 months, comprising 18% of the state population. Almost 9% (8.9%) of children under 18 (65,700) were unable to get needed care.

Health Issues for Utah Mothers and Infants

Utah mothers and their infants generally have good pregnancy outcomes. The low birth weight (LBW) rate has shown a gradual increase over time as it has nationally. In 2003, the state low birth rate was 6.7%. Very low birth weight (VLBW) rates have shown the same increasing trend with a rate of 1.23% in 2003. The percent of preterm births in Utah has gradually increased 9.5% in 2003. The trend in VLBW infants born in tertiary hospitals has seen a decline from 77.5% in 1989 to 66.6% in 2003.

Maternal Mortality - During 2003, Utah's maternal death rate was 0.21 per 100,000 live births, a. rate that has remained relatively stable for the past decade. The Reproductive Health Program uses the ACOG/CDC Maternal Mortality Study Group definition for maternal mortality to include deaths up to 1 year after the termination of pregnancy. This definition differs from the World Health Organization (WHO) and Center for Disease Control/ National Center for Health Statistics (CDC/NCHS) and must be kept in mind when comparing rates with data submitted to NCHS. The expanded definition allows the Perinatal Mortality Review team to examine all pregnancy-related or pregnancy-associated deaths among Utah women.

Fetal and Infant Morality - The state's infant mortality rate has declined since 1989 from 8 per 1,000 live births to 5.0 per 1,000 live births in 2003. This trend reflects the national trend during the same time period. Utah's rate remains lower than the national rate (6.7 per 1,000 lives births) and ranks among the lowest ten in the nation. Utah's fetal death rate in 2003 was 4.9 per 1,000 live births and fetal deaths. This rate has remained relatively stable for the past decade and is considerably lower than the U.S. rate (6.5 per 1,000 in 2001).

Prenatal Care - The percentage of women receiving prenatal care in the first trimester continued to fall from 85.1% in 1994 to 78% in 2003, with the rate reaching an all time low of 76.2% in 1999. The percentage is even lower among Medicaid mothers at 65.3% and among Hispanic women at 61% in 2003. Utah has ranked 49th in the nation in the percent of mothers receiving adequate prenatal care for the past several years. In 1999, Utah hit a 10-year low of adequate prenatal care (Kotelchuck Index) of 58.5%, but has been increasing steadily since 1999. In 2003 Utah's rate was 78.8%, an increase from the previous year of 62.5%. PRAMS data have provided more in-depth information on prenatal care than we have had in the past, such as barriers to care and perception of adequacy of care. These data have enabled us to target interventions to

populations at risk for inadequate prenatal care especially women who get into care late in their pregnancies or not at all. A variety of interventions have been implemented to address the prenatal care issues with apparent impact on the adequacy of prenatal care.

Unintended pregnancy – In 2003, 33.6% of women reported their pregnancy was unintended (either mistimed or unwanted) according to PRAMS data. Although this figure is near the HP2010 goal, much higher rates of unintended pregnancy are noted among younger, non-White, Hispanic, and unmarried women. Women who were covered by Medicaid prior to conception were also more likely to report their pregnancy as unintended yet these women have Medicaid coverage for family planning services. Unintended pregnancy is concerning as women with an unintended pregnancy are less likely to seek early and adequate prenatal care and more likely to expose their fetus to harmful substances or not take multivitamins since they had not intended the pregnancy. Unintended pregnancy also is associated with higher rates of postpartum depression.

Interpregnancy Spacing – Adequate spacing of pregnancies is emerging as an important issue for poor pregnancy outcomes, such as low birth weight and prematurity. Birth data reveal that 10% of women who delivered in 2003 had an interpregnancy interval of less than one year (time from birth of previous child to conception of the current child). Utah exceeds the HP2010 goal of no more than 6% of births to occur within 24 months of the previous birth with a rate of 14.8% in 2002.

Postpartum Depression - Over one quarter of Utah women who recently delivered a live born infant report moderate to severe postpartum depression. A recent comparison of national PRAMS data showed that Utah had the highest rate of reported postpartum depression among the seven states reporting the measure. Using Utah PRAMS data, an analysis of pre-pregnancy body mass index and postpartum depression was conducted by faculty at the University of Utah's School of Medicine. This report found that overweight and obese women were at increased risk of developing postpartum depression.

Overweight/Obesity – The proportion of reproductive aged women who are overweight or obese is increasing in Utah. BRFSS 2003 data indicate that 39.5% of reproductive aged women reported their BMI as overweight or obese. Vital records data indicate that in 2003, 27.9% of women with a live birth were overweight or obese before pregnancy, an increase of 35% since 1993. Of further concern is that 70.2% of overweight/obese women exceeded the Institute of Medicine's recommendations for weight gain. A recent analysis of Utah's Vital Records data showed that among women who delivered via cesarean section, 1 in 6 is attributable to being overweight or obese prior to pregnancy. Primary cesarean sections in 2003 were 12.4% for overweight and 14.6% for obese women compared to 10.2% in women with a normal BMI. An analysis of infant deaths due to perinatal conditions found that obese women had a significantly higher risk of infant death when compared to normal weight women.

Multivitamin Use – PRAMS data from 2003 show that 47.5% of women who had a live birth reported taking no multivitamin in the month before they became pregnant. The rates are higher for Hispanic and non-White women at more than 65% for both. This finding is concerning

because the women who report the lowest use of multivitamins also report the highest percentages of unintended pregnancy.

Tobacco use in pregnancy – A major risk factor for low birth weight babies is smoking during pregnancy. Smoking rates among pregnant women in Utah are lower than national rates. In 2003, 6.4% of Utah women smoked during their pregnancies, while nationally, 11.4% (2002) of pregnant women smoked. Although smoking rates for Utah's population are low, rates are higher among Utah teens, especially those aged 18-19 years (15.4%). According to 2003 BRFSS data, smoking rates for females of reproductive age were 9.6% for 18-34 year olds and 14.8% for 35-49 year olds. Current efforts targeted to reduce smoking among pregnant women include: 1) an educational campaign for health care providers to identify anyone in the household who smokes; 2) media spots targeted to pregnant women who smoke, and 3) an outreach program through Medicaid that screens mothers who smoke, provides nicotine replacement therapy, as well as assistance in quitting.

Physical abuse during pregnancy – An analysis of 2000 – 2001 Utah PRAMS data found that 3.5% of pregnant women reported physical abuse during their pregnancy. The rates were significantly higher for non-White, Hispanic, unmarried, and teen mothers. Of the women who reported being abused before or during pregnancy, 45.8% said they did not seek help from anyone.

Low birth weight - The percent of babies born at low birth weight (LBW) in Utah continues to rise from 5.8% in 1994 to 6.7% in 2003. Health professionals are concerned about this trend since LBW will result in increased costs due to longer newborn hospital stay, health problems, and possible lifelong disabilities requiring special assistance. Low birth weight infants accounted for the largest proportion of infant deaths in the United States in 2002 and low birth weight infants are at risk of morbidity, such as developmental disorders and respiratory infections. When low birth weight outcomes are compared between the Medicaid and non-Medicaid populations, some disparity is evident, as there is an almost 2% difference between the two groups. In 2003, low birth weight among births that were paid for by Medicaid was 7.8% compared to 5.9% among non-Medicaid births. Although Utah's low birth weight rates are lower than the overall U.S. rate (2002-7.8%), the gap is closing as Utah's rate increases. The percentage of LBW births is much higher among African Americans in Utah at 16.4% in 2003 compared to other racial and ethnic groups.

Neonatal Follow Up After Hospital Discharge - A recent analysis of PRAMS data from nineteen states, conducted by CDC, found that Utah had one of the highest rates of early infant discharge coupled with the highest rate of no infant follow up within the first week of discharge. The American Academy of Pediatrics recommends that infants discharged before 48 hours for vaginal or 96 hours for cesarean section deliveries be seen by a pediatrician within two days of discharge. Utah data from 2002 showed that 36% of infants with early discharge were not seen within a week of leaving the hospital. Higher rates of no follow up were noted among Hispanic and non-White women.

Birth defects – Approximately 3% of live born infants in Utah have a medically significant structural birth defect. In a population with a birth frequency of 50,000 approximately 1,500 infants with birth defects may require services to minimize secondary disabilities. Since birth defects are the leading causes of death in the newborn period, identifying pregnancies and infants with major

birth defects in order to better understand their causes is the major activity of the Utah Birth Defect Network. By identifying families at risk, interventions to prevent recurrence of the defect or to provide guidance for appropriate care of the infant can save the family a great deal of distress and save undue costs incurred by the state. The Utah Birth Defect Network provides active outreach to families once a woman is prenatally diagnosed or an infant diagnosed at birth.

Sudden Infant Death Syndrome - Deaths classified as SIDS have continued to decrease since the beginning of the Back to Sleep Campaign in 1994 to a rate of 16.34 per 100,000 or 16 deaths in the state in 2003. While the total number of SIDS deaths has decreased, the number of undetermined deaths is approximately the same as the number of SIDS deaths. The State Medical Examiner attempts to determine if the infant's sleeping situation, such as other persons or objects in the same bed as the infant, could have caused the infant deaths. Due to the difficulty in making this determination when infants are found in co-sleeping situations or adult beds, 11 infant deaths were coded as "other ill-defined and unspecified causes of mortality." The SIDS Program provides outreach material to promote the message of safe sleeping for all infants.

As part of the 2005 Five Year Needs Assessment, the Division's "Survey about Health Concerns for Utah Mothers and Children" identified the following as the most important issues for mothers and infants:

Unplanned pregnancies
Obesity
Depression and other mental health problems
Closely spaced pregnancies
Poor nutrition during pregnancy

These issues have been incorporated into the state priorities, along with concerns for children and youth, including those with special needs.

Health Service Gaps

Family planning services – Access to family planning services is problematic for women without insurance or for whom family planning is not a covered benefit. For several years, legislation for contraceptive equity has been proposed unsuccessfully. PRAMS 2003 data indicated that 33.6% of women reported that their pregnancies were unintended. Rates of unintended pregnancy vary by demographic characteristics of women, e.g. white women reported 32.5% of their pregnancies as unintended while non-white women reported over 50% of their pregnancies as unintended. Variation is seen between Hispanic and non-Hispanic reporting unintended pregnancies, with non-Hispanic women reporting just over 30% of their pregnancies as unintended while Hispanic women reported over 43% as unintended. Another demographic characteristic that reflects differences in unintended pregnancy is mother's income level; women who earn less than $15,000 per year report higher rates of unintended pregnancies (46.9%) than women who earn $50,000 or above (20.7%). More family planning services are needed in the state to provide affordable access for women desiring to plan when they become pregnant and space their pregnancies. Low cost services at the community level would assure that low-income women throughout the state could afford to plan their families.

The MCH Bureau is currently collaborating with Medicaid to submit an 1115 Research and Demonstration Waiver to extend family planning benefits to women who lose Medicaid coverage

60 days postpartum. The waiver will cover a range of reproductive health care services for eligible women up to two years.

Access to Prenatal Care – Access to prenatal health care varies depending on the geographic area of the state. According to Health Professional Shortage Area surveys conducted between 2000 and 2004, there are areas in Utah with high ratios of women of childbearing age to providers, resulting in limited access to a prenatal provider in their area**.** Women in rural communities may have to travel many miles to a provider and/or hospital. More than half of the counties (16 out of 29) are without any obstetrician-gynecologist with several counties reporting as few as 1 provider to 10,000 women of childbearing age. There is a need to promote collaboration to assure better access to consultation services for rural providers.

In 2003, 8,800 Utah women (18.6%) who gave birth to a live baby received inadequate prenatal care. Of these, 3,300 (7.0%) received inadequate care due to late entry into care and 5,500 (11.6%) received inadequate care due to an insufficient number of visits. Women who received inadequate care due to insufficient number of visits were similar to other women with regard to most demographic and behavioral characteristics, however women who received inadequate care due to late entry differed from other women. Based on their demographic and risk profiles, women in the late entry group appeared to be at high risk for adverse outcomes. Inadequate care due to late entry was more common among women who were: under the age of 19, not high school graduates, members of racial and Hispanic minority groups, living in households with annual incomes of $15,000 or less, covered by Medicaid or uninsured, and cigarette smokers. The most commonly reported barriers to obtaining care earlier were: “no money”, “didn’t know I was pregnant”, “too busy”, “did not desire earlier care”, “not having a Medicaid card”, and “couldn’t get an appointment”.

System constraints

Uninsured women **-** The percentage of uninsured women of childbearing ages is increasing in Utah. In 2004, almost 14% of women of childbearing ages were without insurance compared to 10.8% in 2001. The 2004 Utah Health Status Survey found that more than 81,000 women between 18 and 49 years of age had no health insurance. A higher percentage of women under age 35 were uninsured compared with older women. In 2004, 15.5% of Utah women 18-34 years of age had no insurance compared to 11.5% of women 35-49 years of age.

Utah Prenatal Medicaid income eligibility is at or below 133% of the FPL, which prevents many women classified as “working-poor” from qualifying. In addition, Utah is one of only a few states that requires an asset test for prenatal Medicaid eligibility. Utah PRAMS 2003 data indicate that approximately 13,100 pregnant women (26.8%) had no insurance or Medicaid prior to pregnancy. Preconceptional planning, that is preparing for a pregnancy, can result in better birth outcomes and healthier mothers and infants by identifying potential risks for poor pregnancy outcomes before conception and working to reduce these risks. Risks may include pre-existing medical conditions, medication, and lifestyle practices such as diet or use of tobacco or alcohol, or inadequate intake of folic acid before conception. Women of reproductive age need to utilize health care visits before pregnancy. In addition, third party payers need to reimburse these visits to promote healthy pregnancy outcomes.

With the influx of Spanish-speaking immigrants many are without documentation and insurance putting a stress on the health care system. From 1999 to 2003, births to Hispanic women rose from 11.8% to14.2% of live births. According to the Utah Health Status Survey of 2001, 25.8%

of Hispanics had no health insurance compared to 7.2% of non-Hispanic residents who were uninsured.

A relatively small amount of Title V funding is contracted to two agencies in Salt Lake City to assist with the provision of prenatal care services for uninsured pregnant women. The Reproductive Health Program (RHP) has contracts with the Teen Mother and Child Program based at the University of Utah and the Salt Lake Community Health Centers, a network of four community health clinics in Salt Lake City. These clinics provide specialized prenatal care services to teens and low-income women, however this obviously only meets a very small portion of the need.

Geographic disparities - Although most of Utah's population resides in the metropolitan Wasatch Front, residents in rural and frontier areas can be very isolated from health care providers and hospitals. Large expanses of Utah's land are sparsely populated, leaving those who live in these areas very little access to health care services, especially specialty services. Some areas of the state are without an obstetrician/gynecologist. It is interesting, however, that PRAMS data show little difference in the percent of women receiving adequate prenatal care by urban and rural residence.

Disparate health outcomes - Health outcomes for some racial minority and ethnic populations are poorer than those for the population as a whole, such as higher low birth weight and infant mortality rates. For example, the percentage of Black low birth weight infants born in Utah during 2003 was 16.4% compared to 6.6% of White infants. The infant mortality rate for infants born to Black Utah women during 2003 was 19.4/1000 live births compared to 4.7/1000 for infants born to White women. The infant mortality rate for infants born to Hispanic Utah women during 2003 was 5.6/1000 live births compared to 4.7/1000 for infants born to non-Hispanic women.

Family planning services – Currently some local health departments in the state are no longer able to receive 340B discounted oral contraceptives or Depo Provera. Despite development of informal purchasing collaborative among some of the local health departments, several are in danger of losing their ability to subsidize oral contraceptives or Depo Provera at reasonable cost to low-income women. The greatest impact of the loss would be in rural areas without community health centers or Planned Parenthood clinics. The Primary Care Network cannot completely fill this void as the enrollment fee has proved a barrier for some women and non-citizens are not eligible. Due to state laws, local health departments must obtain written parental consent to provide family planning information or services to unmarried minors. The greater impact of this law is seen in rural areas without community health centers or Planned Parenthood clinics. Emergency contraception (EC) information or services is not permitted by at least one local district's health board and it has been reported that some pharmacies in the state will not fill prescriptions for EC**.**

Mental health services - Another health service gap for women of reproductive age in Utah is lack of coverage for mental health care services and accessible mental health services. Although data on availability of mental health care services for women of reproductive ages have not yet been compiled, anecdotal evidence indicates that this is a problem. PRAMS data indicated that postpartum depression occurs among approximately 25% of Utah women who report moderate to severe depression in the first few months after delivery. The UDOH Perinatal Task Force

subcommittee is assessing the gaps in mental health services more thoroughly in order to develop strategies to address this important issue.

Needs of minority racial and ethnic populations

Better strategies that address the special needs of minority racial and ethnic populations need to be developed to improve access to services to achieve healthy outcomes. A growing population of undocumented individuals ineligible for most public programs, such as presumptive eligibility for prenatal care, Medicaid (other than Emergency Medicaid), CHIP or the Primary Care Network, has stretched community health centers and local health departments to their limits to provide severely discounted services or unfunded care for this segment of the Utah population. In addition to improving accessible health care for this population, improved access to translation services, more ethnic health care providers and sensitivity to the unique needs of culturally diverse populations are needed to facilitate better health care. Local health departments have increased staff that is bilingual in order to meet the needs of the growing Spanish-speaking populations they serve. More materials and resources have been translated and made available for the Spanish-speaking populations, e.g., the Reproductive Health Program website includes a Spanish section so that Spanish speaking individuals can access the same information that English-speaking individuals can. Other programs have also developed websites for the Spanish-speaking populations. The 2005 Legislature passed a bill that restricts Utah driver's licenses to Utah residents with documentation. Undocumented individuals now will be issued a driving permit that cannot be used by any government entity in the state (regardless of funding source, i.e., WIC) as identification.

Strengths and weaknesses of the system for mothers and infants

Utah has a strong tertiary care system for perinatal and neonatal health care. Referrals are received from the entire intermountain west region. These tertiary care centers are all situated in a relatively central geographic location around Salt Lake City. In reviewing the data on the percent of very low birth weight infants born in tertiary centers, the trend is going downward, with more very low birth weight infants being born in secondary level hospitals. A couple of hospitals have established newborn ICUs and added neonatologists to their staff, however, they did not have the corresponding high-risk specialists for the mothers; these hospitals have not been included in the category of tertiary perinatal centers. Collaborative relationships need to be fostered to encourage consultation and referral of high-risk pregnant women as appropriate to tertiary centers. Case review data from the Perinatal Mortality Review Program indicate that prenatal care providers need to be encouraged to refer their high-risk pregnant women with chronic health problems to specialist care as well as support services (e.g. dietitians, tobacco cessation programs and substance abuse treatment) to promote optimal outcomes. Data also illustrate the need for promotion of adequate prenatal risk assessment for all pregnant women, such as screening for tobacco, alcohol and substance use, HIV status, history of previous low birth weight and/or fetal-infant deaths and psychosocial issues.

Eligibility for Utah's Prenatal Medicaid Program remains unchanged at 133% of the federal poverty level and continues to require an asset test for enrollment. As a result, many women do not qualify and find it difficult to access prenatal services. The state initiated the Primary Care Network (PCN) to provide preventive health services to an additional 25,000 Utahns, however PCN does not cover prenatal care and undocumented women are not eligible for enrollment.

Approximately 9,000 women who qualify for Prenatal Medicaid each year lose eligibility two months after delivery, leaving them without a third party payer for family planning services.

Without access to long-term family planning, adequate spacing of pregnancies for optimal maternal and child outcomes becomes very difficult. Although clinics offer family planning services on a sliding scale basis, they are limited in their ability meet the high demand for the services. Utah does not allocate any state dollars to family planning services other than the state match for Medicaid.

Large, vast areas in Utah have high ratios of women of childbearing age to providers, resulting in limited access to a reproductive health care provider in these areas. More than half of Utah's counties are without any obstetrician/gynecologist for the management of high-risk pregnancies. Four rural counties have no prenatal care or family planning provider of any kind. Women in these counties must travel many miles to see a provider for reproductive health services or to deliver their infants.

Health Issues for Utah Children

The 2001 Utah Health Status Survey and the recently released 2003 Health Status Survey are the primary sources for information regarding health insurance coverage and access to care for children. The 2001 report contains finer stratifications on certain indicators since it includes two years of data and has been available for additional analysis.

The following information is from the 2001 Utah Health Status Survey:

- Hispanic children were less likely than non-Hispanic children to lack health insurance coverage (20.4% vs. 5.3%).
- Children under 200% of the federal poverty level made up 89.5% of uninsured children in the survey. Of those children in households whose incomes were below the poverty level, 15.2% had no health insurance coverage. The percentage without coverage for children in households from 101% to 200% of poverty was 10.1%.
- Additionally, 3.3% of insured children experienced a problem or delayed getting needed medical, dental, mental health, or other care in the previous twelve months because the service was not covered by their insurance.

The following information is from the 2003 Utah Health Status Survey:

- 2.2% of Utah children were reported to be in "fair" or "poor" health, for an estimated 16,400 Utah children.
- Of the children newborn to 17 years of age, 7.3%, or 54,500 children, were estimated to be without any type of health care coverage at the time of the survey.
- The most common reasons for lack of coverage were "can not afford premium," and "lost job" (66.3% and 47.5%, respectively). This finding represents a marked increase for the "lost job" category, up from 29.5% in the 2001 Survey.
- Of those who were uninsured at the time of the survey, a majority (55.1%) had lacked coverage for at least one year.

Health Insurance Coverage- As the lead agency in public health, the Utah Department of Health is committed to reducing the numbers of uninsured children, currently at 8.2%. State data indicate that 10.2% of Utahns are uninsured, an increase from 9.1% in 2003. The uninsured in Utah has gradually increased over the previous several years. State staff, along with many partners, provided the leadership to implement a state model Children's Health Insurance Program in 1998 to address the problem of uninsured children in Utah. The Utah CHIP eligibility level is 200% FPL for children from birth to18 years of age. CHIP enrollment quickly increased well beyond the 21,000 children that were expected to enroll, exceeding the program's budget in December 2001. The enrollment crisis was addressed with capped enrollment, periodic open enrollment periods, imposition of a quarterly premium, and reduction in dental benefits. Open enrollment periods were

short and did not follow a schedule, yielding between sometimes more than 9,000 applications. The program did not maintain waiting lists so that parents who missed the open enrollment periods had to wait for the next open enrollment. The 2004 and 2005 Legislatures allocated additional state funds for the program to restore dental benefits and increase enrollment capacity to approximately 40,000 children. The expectation is that with the expansion of enrollment capacity that the program will be able to maintain open enrollment.

A second strategy to address the need for insurance for children was legislation to eliminate the Medicaid asset test with the intent of moving children from CHIP to Medicaid and opening up the CHIP slots to more children. However, this proposed legislation did not pass in the 2005 Legislative Session. According to 2004 data from Center on Budget and Policy Priorities, Utah is one of six states with a Medicaid /SCHIP asset test, preventing some children that might otherwise be eligible for Medicaid to be enrolled in that program. The Covering Kids and Families Coalition, part of a project funded through a Robert Wood Johnson grant, provided a forum for government and non-profit organizations to work together to address CHIP and Medicaid issues including outreach and policy development. The lead agency is Voices for Utah Children and Division staff participates in monthly meetings and work with the project to further its goals through subcommittee work.

Financial barriers continue to exist for families and children whose condition and/or services are not covered by third party payers (e.g., pre-existing conditions, therapy, orthodontia, dental and surgical exclusions). Limited provider panels offered through managed health care plans reduce accessibility to pediatric specialty care. The Child Health Insurance Program (CHIP) has improved basic medical coverage for uninsured children but specialty services are not covered.

The impact of the new Medicare Part D benefit on state EPSDT and Medicare dual eligible individuals throughout the state will not be fully realized until the new benefit becomes effective on January 1, 2006. At this time we have identified a very limited number of children who either are or can be characterized as dual eligible. Utah is currently taking steps to ensure that any child who is dual eligible is identified and parents made aware of the potential changes in their benefits. Assistance may be available to any eligible child for help in paying the premium and co-pay costs of Medicare Part D covered prescriptions.

Access to Care - The Utah 2003 Health Status Survey indicated that 28.1% of children had no regular medical checkup. Three percent of parents reported that they had no usual place of health care for their children.

The following information is from the 2001 Utah Health Status Survey:

- For parents who experienced a problem or delayed getting care because they could not afford the services, dental care was more difficult to afford than medical care, 68.5% and 47.8% respectively.
- Almost 4, 000 (3,900 or 0.5%) parents reported that the usual source of health care for their children was the hospital emergency room
- Of the families who experienced a problem or delayed getting care for their children because they could not find the services in their area, medical care was more difficult to find than dental care, 57.5% and 32.5% respectively
- Children in the Southeastern Utah District Health Department had the most problem finding needed health care services, 8.5% compared to the state average of 1.5%.

The following information is from the 2003 Utah Health Status Survey:

- Over seven percent (7.3%) of parents with insurance coverage for their children indicated that they delayed or had problems getting care (medical, dental, mental health, or some other type of care) for their child because they could not afford the services.

Medicaid's shift from a fee-for-service system to managed care has made tracking of services for maternal and child health populations very difficult, if not, impossible. For example, tracking prenatal, family planning, EPSDT services, or immunizations is almost impossible because of the shift in data ownership from Medicaid to the Managed Care Organizations (MCO). Medicaid is able to track claims data, but the MCOs are not able to provide encounter data for their members due to inadequate computer tracking systems. Medicaid is working with the MCOs to improve access to needed data to track outcomes, costs, services provided, etc. Long-range studies will be needed to assess the full impact that managed care has had on the Medicaid population in the state.

Medical Home - The Utah Collaborative Medical Home Project, despite the loss of federal grant funding, is providing information to medical providers through its website at www.medhomeportal.org. Various partners, including the University of Utah and the Utah Department of Health, support the Project. The Division of Health Care Financing, the State Medicaid agency, is providing funding over three years, FY2004-2006, through the Commonwealth Fund's Assuring Better Child Development (ABCD) II grant. These funds are designated for developing a module on infant development. The Child Adolescent and School Health Program is promoting the Project through distribution of print materials, brochures, bookmarks, pens, and other materials at local, state and national meetings. The Project is exploring the possibility of working with other states in their efforts to promote medical home. The Department of Health, Bureau of Children with Special Health Care Needs received a three-year grant for Integrated Services, which will help support some of the Department's efforts to promote medical home.

Childhood Immunizations - In 2000 68.2% of Utah children were immunized for 4:3:1:3:3, which was below the national average of 72.8%. The most recent data for 2003 show that 78.8% of Utah children were immunized for 4:3:1:3:3, which is closer to the national average of 79.4%. The Immunization Program continues to work with private providers, local health departments, community health centers and other partners to increase the immunization rates for children. The Immunization Program resides in the MCH Bureau, which has greatly enhanced the Program's efforts to improve immunization rates for young children, adolescents, college students and adults. Although the Immunization Program addresses immunizations across the lifespan, a great amount of staff efforts revolves around ensuring that children are adequately immunized.

Oral health and water fluoridation – The 2000 Utah Oral Health Survey indicated that 58% of 6 - 8 year old children in Utah had experienced dental caries compared to 52% nationally. The percentage of untreated dental caries among 6 - 8 year old Utah children, which is an important measure of access to dental care, was 22%. The national average for this measure is unclear. Only 29% of Medicaid children access dental services compared to nearly 70% for CHIP children. The 2000 Utah Health Survey indicated that 50% of 6-8 year old children had at least one dental sealant.

In November 2000, Salt Lake and Davis Counties voted to fluoridate their water supplies, with implementation completed by October 2003 for most water districts. Water fluoridation in these two counties increased access to fluoridated water from 3% to 52% of the state's residents and 67% of the urban residents. However, only about 1% of Utahns residing in rural areas benefit from community water fluoridation or optimum levels of naturally fluoridated water. In November 2004, fluoridation was again on the ballot for Davis County residents and they voted by a narrow margin to continue fluoridating their water supplies. This issue has been hotly contested in the State Legislature with numerous bills approaching the issue from a variety of mechanisms to try to undermine this important public health intervention for Utah populations.

Nutrition and Physical Activity - Healthy eating habits and regular exercise play an important role in the health of children, and will have life-long effects as they carry these habits into adulthood. According to the 2003 Youth Risk Behavior Survey, 7% Utah students were overweight and 11.3% were at risk for overweight, a steadily increasing number following the national trends of 13.5% and 15.4% respectively. According to the 2001 Utah Health Status Survey, 62.3% of children were reported to have engaged in regular moderate exercise and 55.6% were reported to have engaged in regular vigorous exercise. The increasing trend in children and youth who are overweight or at risk of overweight is a priority for the Utah Department of Health.

Mental Health - The State Division of Substance Abuse and Mental Health (DSAMH) in the Department of Human Services has received a five-year grant award to build infrastructure for mental health services for children and youth (UT CAN – Utah Transformation for Children and Adolescent Network). The Utah Department of Health has a seat at the advisory committee for the grant and will be working with DSAMH staff to provide input and support for the grant activities. Other Division and Department staff has been appointed to the subcommittees for the grant and will participate in the work of these subcommittees to promote the importance of the link with primary care providers and private providers, as well as the importance of family mental health on the mental health of children and youth. The DSAMH grant ties in well with the Division's mental health priorities.

Mental health issues have been identified as one of the top five priorities in the Division Survey about Health Concerns for Utah Mothers and Children conducted as part of the five year needs assessment. The subcommittees of the MCH/CSHCN Advisory Committee identified both postpartum depression and mental health of children and youth as top priorities for the populations they represent. The Adolescent Health Advisory Committee identified mental health issues as its top priority. The scope of mental health issues includes a variety of issues for mothers, children and adolescents related to primary prevention and screening. Issues that are included under mental health are social-emotional screening for infants and toddlers and mothers, positive youth development, self-esteem building, depression prevention, and suicide prevention. Statistics for abuse and rape are included since they impact the mental health state of children and the long-term health behaviors and mental health status of adults.

The 2003 Utah Youth Risk Behavior Survey of students in grades nine through twelve revealed the following information:

- Almost 27% of Utah students reported that they had felt so sad or hopeless almost every day for two weeks or more in a row that they stopped doing some usual activities

- Slightly more than 16% of Utah students reported that they had seriously considered attempting suicide
- More than 12% (12.4%) of Utah students reported they had made a plan about how they would attempt suicide
- Slightly more than 3% (3.1%) of Utah students reported they actually attempted suicide two or three times
- Almost 8% of Utah students reported that they had been hit, slapped, or physically hit on purpose by a boyfriend or girlfriend
- The percentage of Utah students who had been physically forced to have sexual intercourse when they did not want to was 8.5%.

Mental health screening and early recognition is an important approach that will be promoted with primary care providers in order to get those in need into appropriate services and treatment, if needed. The Bureau of Maternal and Child Health has hired a Children's Mental Health Prevention Specialist to provide additional capacity to further explore prevention and screening options for women and children. This Specialist, a licensed mental health professional, has experience in prevention, clinical treatment, and capacity development for system improvements. Additionally, the Utah Pediatric Partnership to Improve Healthcare Quality, a joint project with funding from several sources including Title V, Title XIX, and a Commonwealth Fund grant, has engaged in provider training for 20 pediatric practices to assist them in screening for social emotional delays in infants and toddlers.

Violence and Injury - In Utah, injury is a significant public health problem and a leading cause of death and disability. It is the leading cause of death for people age 1 – 44 years and the leading cause of years of potential life lost in Utah. Each year injuries (intentional and unintentional combined) account for over 150 deaths, 1,700 hospitalizations, and 77,000 emergency department (ED) visits among Utah children ages 1-19 years.

During 1999-2003, the rate of injury deaths for Utah residents ages 1-19 years was 19.9 per 100,000, accounting for 64% of all deaths in this age group. The proportion of deaths due to injuries in children and youth increase with age: 44% of deaths in ages 1-4, 50% of deaths in ages 5-9, 53% of deaths in ages 10-14, and 73% of deaths in ages 15-19 were due to injuries. Of these deaths, 69% were due to unintentional injury, 20% due to suicide, 5% due to homicide and 4% due to other/undetermined intent. Motor vehicle crash was the leading cause of injury deaths in this population.

During 1999-2003, the rate of hospitalizations due to injuries for those aged 1-19 years was 221.5 per 100,000 persons accounting for 9% of all hospitalizations for this age group. Unintentional injury accounted for 86% of the injury-related hospitalizations, followed by self-inflicted injuries at 10%. Based on the NCHS 50 Leading Causes, unintentional injury was the second leading cause of hospitalization for Utah children ages 1-19 years.

The rate of injuries resulting in Emergency Department (ED) visits was 9,884 per 100,000 persons, for Utah children ages 1-19 years during 1999-2003, accounting for 43% of all ED visits for this age group. Unintentional injury accounted for 97% of these injury-related ED visits. Based on the NCHS 50 Leading Causes, unintentional injury was the leading cause of ED visits.

These numbers do not take into account the injuries treated in clinics, doctor's offices, schools, work sites and homes. It is difficult to determine the full economic impact of injury (medical costs, lost wages, disability, etc.). However, hospital charges for injuries in Utah average over $18 million per year and ED costs average $44 million per year for children and youth

between the ages of 1 and 19 years.

The rates of death and hospitalization from intentional injuries are lower than for unintentional injuries. Nevertheless, suicide and interpersonal violence have serious and far-reaching personal, social, and economic consequences. Suicide and attempted suicide were the leading causes of intentional injury death and hospitalization. While assaults were the leading cause of intentional injury ED visits. During 1999-2003 there were 156 suicide deaths and 41 homicide deaths for Utah children ages 1-19 years. During 1999-2002, Utah had the 8th highest suicide rate in the nation for youth aged 15-19 years. Suicide prevention remains a high priority. Due to the social stigma and difficult legal issues related to suicide, child abuse, intimate partner abuse, rape and sexual assault, intentional injuries are under-reported.

Motor Vehicle Crashes - Based on the NCHS 113 Leading Causes, motor vehicle crash was the leading cause of death for Utah residents ages 1-19 years. Thirty–one percent of all child deaths resulted from motor vehicle crashes. The mortality rate for Utah children between 1 and 19 years was 13.2 per 100,000 from 1999-2003. Motor vehicle crashes were the leading cause of injury hospitalization for Utah residents ages 1-19 years. More than 2600 hospitalizations for children in this age group resulted in more than $40 million in inpatient charges. Motor vehicle crash prevention will continue to be a high priority in Utah.

Safety Restraints - The greatest risk for children being killed or injured from a motor vehicle occupant crash is riding unrestrained. Utah fares well for restraint use, although more work needs to be done to promote use. The 2003 Utah Department of Public Safety observational survey found that 84% of children birth to10 years were restrained. More Utah teens report using their seatbelts than teens nationally. According to the 2003 Youth Risk Behavior Survey, 6% of Utah teens rarely or never wear seatbelts compared to 18% nationally. A significant concern is the low rate of booster seat use among children age 4-8 years, with only 28% of children in this age rode in booster seats according to a 2004 statewide survey. Children in this general age range may have outgrown child car seats, but they are too small to be safely restrained by adult seat belts. UDOH, local health departments, and other partners are conducting surveys and implementing community-based programs to increase booster seat use.

Suicide - Suicide is the second leading cause of death among Utah residents 1-19 years. For the years 1999-2002, Utah had the 8th highest suicide rate for ages 15-19 years in the nation. During 1999-2003, suicide accounted for 22% of all deaths among Utah teens age 15-19 years. Males accounted for 88% of these teen suicide deaths. According to the 2003 Youth Risk Behavior Survey, 8% of Utah teens attempted suicide during the past year. In 2003, 16% of Utah students in grades 9 – 12 had seriously considered attempting suicide during the 12 months before the survey. Although teen suicide deaths are significantly higher for males, females were more likely to be treated in the hospital or emergency department for self-inflicted injuries than males.

Suicide has serious and far-reaching personal, social and economic consequences. Suicide and attempted suicide were the leading causes of intentional injury death and hospitalization. Suicide prevention remains a high priority for the Utah Department of Health which partners with a number of other agencies and partners to develop strategies to address prevention, intervention and treatment.

Tobacco Use – Tobacco use in general is lower in Utah compared to the rest of the nation. Youth tobacco use follows the state overall tobacco use rates. According to 2003 YRBS data, 9.1% of Utah students (9 – 12 grades) smoked a whole cigarette for the first time before age 13, compared to 18.3% nationally. Despite substantial declines in youth smoking since the mid-nineties, more than 13,000 Utah students in public middle and high schools reported that they had smoked cigarettes in the past 30 days (Utah Youth Tobacco Survey 2003). No difference was found in smoking rates between male and female students. Utah high school students reported cigar smoking as the second most prevalent form of tobacco use.

Substance Abuse - While most categories of alcohol and marijuana use among youth in Utah are generally below the national average, Utah has statistically similar rates for cocaine use, sniffing or huffing, and use of heroin, methamphetamine, steroids, and needles according to the 2003 Youth Risk Behavior Survey (YRBS) data below.

Of Utah students in grades 9-12,

- 17.4% had their first drink of alcohol other than a few sips before age 13 compared to 27.8% nationally
- 5.8% tried marijuana for the first time before age 13 compared to 9.9% nationally
- 11.4% used marijuana one or more times during the past 30 days compared to 22.4% nationally
- 7.1% used any form of cocaine, including powder, crack, or freebase one or more times during their life compared to 8.7% nationally
- 14.6% sniffed glue, breathed the contents of aerosol spray cans, or inhaled any paints or sprays to get high one or more times during their life compared to 12.1% nationally
- 2.9% used heroin one or more times during their life compared to 3.3% nationally.
- 6.0% used methamphetamines one or more times during their life compared to 7.6% nationally
- 6.6% took steroid pills or shots without a doctor's prescription one or more times during their life compared to 6.1% nationally
- 3.3% used a needle to inject any illegal drug into their body one or more times during their life compared to 3.2% nationally

Adolescent births - The birth rate for Utah females ages 15-17 was 17.5 per 1,000 females compared to the national rate of 23.2 per 1,000 in 2002. The birth rate for Utah females age 15-17 in 2003 was 16.3, showing a declining trend for Utah adolescents. National data for 2003 birth rates were not available. The birth rate for Utah Hispanic females age 15-19 in 2003 was 107 per 1,000. The birth rate for all Utah females age 15-19 in 2003 was 34 per 1,000. This overall rate reflects the influence of the rate for the older teenage population, 54% for age 18-19. In Utah, it is not uncommon for adults to marry and begin families in their late teenage years.

The Division is responsible for the Section 510 abstinence education federal funding and thus the Adolescent Health Coordinator partners with a number of agencies to coordinate teen pregnancy prevention efforts. The Utah Abstinence Education Program has funded eight programs with federal Abstinence Education Title V funding to promote abstinence only until marriage. These programs address local needs and use a positive youth development focus that builds the self esteem and skills of children from age nine to fourteen to help them resist social pressures of substance use and sexual activity. These programs, generally implemented in public school

settings, provide information regarding the health dangers of sexual activity, including sexually transmitted diseases. Utah is an abstinence-based education state and does not allow the collection of sexuality information on the Youth Risk Behavior Survey, leaving Utah with no formal statistics on adolescent sexual behavior.

Sexually transmitted infections - The chlamydia infection rates among teens (15 – 19 years of age) have increased significantly since 1995 from 367.4 per 100,000 to 621.7 per 100,000 in 2003. During 2003, the teen chlamydia rate for females was 1049 /100,000 and the rate for males was 193/100,000. The rate increase may be due to development of easier less invasive testing methods that teens are more willing to do than with previous methods that were invasive examinations.

Childhood asthma - According to the 2001 Utah Health Status Survey, 5% of children were under medical care for asthma. The rate of children hospitalized for asthma (ICD-9 Codes: 493.0 - 493.9) was 18.6 per 10,000 children under five years of age in 2003. Six percent of children had been exposed to cigarette smoke inside the home. Children who lived in the Southeastern and TriCounty health districts were most likely to be exposed to cigarette smoke in the home, 17.6% and 16.8% respectively. The Department began an Asthma Program in 2001 to address asthma among all ages in Utah. Utah Inpatient Hospital Discharge Data indicate that the rates of hospitalizations, per 10,000, for children from 0-18 were 8.6 in 2002 and 8.5 in 2003. In 2004 the state Legislature passed legislation allowing students to carry inhalers at school for self-medication for asthma. The legislation was needed due to the state's zero tolerance policy for drugs in schools.

As part of the 2005 Five Year Needs Assessment, the Division's "Survey about Health Concerns for Utah Mothers and Children" identified the following as the most important issues for children and adolescents:

Lack of physical activity
Obesity
After school supervision
Teen pregnancy
Depression and other mental health problems

These issues have been incorporated into the state priorities, along with concerns for the other two populations. In an effort to address these issues, the Title V agency has joined in a multi-program effort to measure childhood obesity, participated in effort to improve the system of out-of-school-time services, funded local abstinence education projects, and hired a children's mental health specialist.

Health Service Gaps for Children

The 2004 Utah Health Status Survey indicates that 8.2% of children birth to17 years of age representing more than 63,000 children were estimated to be without any type of health care coverage. The 2003 Health Status Survey indicated that 8.8% of children were unable to get needed medical, dental, or mental health care in the previous 12 months. Previous problems with enrollment into the Utah CHIP Program have now been mitigated with additional state funding that should be sufficient to ensure that enrollment capacity is adequate. Mental health services for children may be difficult to access, especially for very young children. Pediatric psychiatrists are limited in the state, making it difficult to access these important providers for children, especially

in complex cases of mental disorders. The mental health system in the state is based on community mental health centers located throughout the state, with Medicaid having carved out these services to the mental health centers. Perception has been that accessing services through the community mental health centers is very difficult unless the individual has significant complex long-term mental health disorders.

System constraints

With Utah's large family size and low per capita income, economic constraints in utilizing and paying for health care are inevitable. Given the geographic makeup of the state, access to pediatric services in the rural areas is limited due to the high ratio of children to pediatricians. Access to pediatric specialists is basically limited to the Wasatch Front area, with those families living in the rural and frontier areas of the state having to travel to the Wasatch Front to obtain specialty services for their children.

Utah CHIP provides greater access to affordable health insurance for children from many working families, primarily the working poor (at or under 200% of the federal poverty level). Policy and outreach efforts in Utah have enabled the state to enroll more children in Medicaid and prevent children from being disenrolled in CHIP. The increase in state funds to the CHIP program has increased enrollment capacity to an adequate level to meet the need of uninsured children. Strong partnerships, through the Covering Kids and Families Coalition, have explored legislative and agency rule changes that would improve the Medicaid and CHIP systems by dropping the asset test for children. Dropping the asset test for Medicaid eligibility for children would enable more children to be enrolled in Medicaid, rather than CHIP, building system capacity for more children for health coverage. However, this legislative initiative did not pass in the 2005 Legislative Session.

Increases in dental and prenatal provider reimbursement rates are vying with each other as well as other numerous competing budgetary requests and needs, with little budget relief in sight. Both groups of providers have approached the Medicaid Medical Advisory Committee to provide information on the need for higher compensation for care. The Division will continue to keep a pulse on these two important issues for mothers and children in Utah.

With the growing populations of children from ethnically diverse families, the health care system is challenged to address their needs. Language barriers, concern about accessing government services by parents who are not documented, even when the children are citizens, continues to be a barrier to health care coverage and access to services.

The relationship between the local health departments (LHDs) and the MCH/CSHCN programs has been strong, although reduced or flat state and federal funding as well as an increased focus on promoting core public health functions has resulted in some additional challenges. The Division is providing additional technical support and training to help address these issues for the local health departments.

Mental health providers, especially those specializing in children's mental health, are limited, in part due to the mental health system in the state which is a Medicaid carve-out serving primarily the chronically mentally ill, but not necessarily those with acute conditions.

Needs of Minority Racial and Ethnic Populations

Health outcomes for some racial minority and ethnic populations are poorer than those for the population as a whole. Strategies that address the special needs of minority racial and ethnic populations need to be developed to improve access to services to achieve healthy outcomes.

Improved access to translation services, more ethnic health care providers and sensitivity to the unique needs of culturally diverse populations will facilitate better health care

A higher percentage of Hispanic than non-Hispanic children, 20.4% vs. 5.3%, did not have health insurance coverage according to the 2001 Health Status Survey. However, Hispanic children were more likely to have received routine medical check-ups (84.3% vs. 72.1%) and experienced fewer injuries in the past 21 months (6.5% vs. 11.7%) than non-Hispanic children.

The proportion of Hispanic children under 5 enrolled in Utah WIC (33.1%) is about the same as the U.S. proportion for the same group (32.2%). The proportion of pregnant and postpartum women (28.5%) is higher in Utah than nationally (21.5%). For the Utah births in 2002 14.2% were to mothers who reported they were Hispanic. Since 33% of Hispanic women are enrolled in WIC, it appears that they are utilizing these services effectively.

The Utah WIC Program has adapted to the cultural needs of the Hispanic population by modifying food packages, which may include substituting peanut butter for beans when requested. Recipes using substituted beans are also available for participants. Many WIC clinics offer their classes in Spanish and have educational materials in Spanish. WIC participants who speak only Spanish and have no designated primary care provider are referred to a Spanish-speaking provider when available.

Local health departments and community health centers have worked to hire bilingual health professionals to better meet the needs of their changing client population. Since the major ethnic group in Utah is Hispanic, clinics have attempted to address the needs of the Hispanic population through hiring of bilingual staff. However, there are other groups in the state that are growing in numbers that are hard to reach due to language barriers, cultural barriers, and provider acceptability. However, much remains to be done in this arena. Staff needs more training on cultural awareness and it needs to be recognized that cultural sensitivity incorporates more than language, country of origin, or skin color. Salt Lake Valley Health Department hired a Spanish-speaking male nurse, which has presented some unexpected additional challenges for the home visiting nurse programs as evidenced by calls to the LHD and the state to verify the existence of the program and his employment.

Utah programs have worked to promote increasing awareness of the Department of Justice regulation announced in 1999 that assures families that enrolling in Medicaid or the Children's Health Insurance Program will not affect immigration status. While programs, such as the Covering Kids and Families Project, have promoted this information, many families remain skeptical about applying for any government programs for fear they will be reported to Immigration and Naturalization Services or that their immigration status will be affected.

Strengths and weaknesses of the system of care for children and youth

Access to Health Care

The majority of maternal and child health services are provided through the private sector and managed care organizations. The 10 community health centers and the Wasatch Homeless Clinic provide primary care to underinsured and uninsured MCH populations. Six of these community health centers are located in rural areas of the state. Three migrant farm worker clinics are co-located with Wasatch Front community health centers and a fourth clinic is located in Brigham City. Unfortunately, many of Utah's Hispanic workers, especially along the Wasatch Front, are not engaged in farm work and therefore do not qualify for these services. Eight of the twelve local health departments continue to offer well child services. Whenever necessary, referrals are made to providers and/or clinics within the community for follow-up of identified health

concerns, and the local health departments strive to assist families in identifying primary health care providers for their children. The Division of Community and Family Health Services has worked with the local health departments through a variety of programs to encourage them to foster medical homes for children and to redirect their resources from direct services to core public health functions. Medicaid's system of health care along the urban areas of the state is managed care or PPO type systems. Medicaid has experienced difficulty in maintaining MCOs willing to continue to contract for service coverage for Medicaid populations in the state due to economic crises that have forced some of the MCOs out of the Medicaid market. MCOs have spread to some rural areas of the state; however, Medicaid participants in rural areas do not have to enroll with a MCO for health care.

Lack of Health Insurance

The 2003 Legislative session provided additional funds for needed programs and projects. Additional funding was appropriated for an increased enrollment of 12,000 children for CHIP, which will allow the program to maintain open enrollment.

In 2002 only 29% of children enrolled in CHEC (Utah's EPSDT) had utilized dental services. However, utilization of dental services by children enrolled in CHIP was significantly higher at approximately 70%. Unfortunately, due to budget constraints, CHIP dental benefits were reduced to basic preventive and emergency care in January 2002. In July 2003, the dental benefits for CHIP were restored and the enrollment cap was raised from 24,000 to 28,000 children. Enrollment capacity has been increased to approximately 40,000 children with the increase in state funds for the program in 2005.

The public health system in Utah is hampered in providing services to all in need due to funding shortages, staffing shortages, and other challenges. Utah is faced with a growing population of families without insurance, especially those of undocumented citizenship status, placing a stress on a health care system with limited resources. Local health districts and community health centers in the state have been forced to place limits on the number of individuals seen due to limited resources. Limited resources also prevent hiring additional public health nurses to provide services at needed levels or more in-depth services to the maternal and child populations of the state, such as care coordination, home visiting services, and grief support to families that experience SIDS. Although public health nurses have been trained across the state as Child Care Health Consultants, budget and staffing shortages prevent the local health departments from providing this service.

One of the strengths of the system is that the Utah Department of Health is collaborating with several organizations, under the leadership of the Utah Chapter of the American Academy of Pediatrics, the Intermountain Pediatric Society, to improve health care services for children through primary care provider education and quality improvement projects. This project, the Utah Pediatric Partnership to Improve Healthcare Quality, provides an opportunity for practices to improve components of well child visits, developmental screenings, and social-emotional screenings for infants and young children. The process involves an initial learning session followed by conference calls, follow-up calls, chart audits, and technical assistance visits for a group of practices around a specific topic. While results vary across the individual practices, results from the group of practices are demonstrating improvements such as an increase from an initial two out of ten practices to nine practices out of ten using standardized social-emotional screening tools. The downside of this successful collaborative project is that it is dependent on soft funding at this time.

Children with Special Health Care Needs

To describe the Utah population and to identify needs and gaps in service systems a number of community, state, and national survey data and sources were used including: National CYSHCN Survey; Utah Department of Health 2000 CSHCN Survey; 2000 National Census Data; 2003 Utah Governor's Office of Planning and Budget (GOPB) Population Projections; and, 2003 Transition Focus Group for the Utah Collaborative Medical Home Project (UMHCP).

Prevalence of Children with Special Health Care Needs

The Utah CSHCN survey was completed in December 1999 with funding from the MCHB/State Systems Development Initiative (SSDI) grant. A total of 742 children were identified by the survey as having chronic special health care needs, which suggested an 11.0% statewide prevalence of CYSHCN. This prevalence figure was lower than had been expected compared to national prevalence rates, which ranged from 16% to 19%. Utahns are healthier in many aspects, and while a prevalence rate of 11.0% seemed within the range of possibilities, it was low enough to warrant investigation of possible methodology factors that may have resulted in an artificially low rate. After review of the methodology, it was determined that Utah rates were lower primarily in the younger age groups. Possible factors which might contribute to this finding include: 1) Utah children have fewer of the problems that affect younger children, or 2) compared with children in other states, children in Utah are less likely to be identified as having conditions while they are young.

Results of the National CYSHCN Survey indicate that 11.0% of Utah children have a chronic illness or condition that requires special health care. Based on this estimation and applying the GOPB 2004 population estimates, approximately 107,331 Utah children and young adults have special health care needs. The most common condition was behavioral conditions, such as attention deficit hyperactivity disorder, accounting for 35% of children with special needs. The second most common condition among Utah children was asthma or respiratory conditions accounting for 19.3% of CYSHCN. Prevalence of special health care needs increases with the child's age, possibly because conditions are identified later or problems develop as a child matures.

Approximately 3% of live born infants in Utah have a medically significant structural birth defect. In a population with a birth frequency of 50,000 approximately 1,500 infants with birth defects may require services to minimize secondary disabilities. Of these infants, a higher proportion is born prematurely compared to the overall population of infants born. Moreover, infants with birth defects are the highest contributor to neonatal and infant mortality, surpassing prematurity, SIDS, and other causes

Health Status and Risk Factors

The Utah CSHCN Survey addressed health status and certain risk factors of this population. Overall, 9% of children with special health care needs were reported with "fair" or "poor" health. Fair/poor health status was more common among children in the youngest age group (age birth-5, 10.3%). Hispanic children (14.9%) and children in poverty (18.9%) were also more likely to have been reported in fair/poor health. Fifty-nine percent of CSHCN had one or more days out of the last 30 when their physical health was "not good" (including illness and injury). On average, CSHCN experienced 3.9 sick days in the last month before the survey. Approximately 42% of CSHCN were reported to have one or more days in which their mental health was "not good" (including stress, depression, and emotional problems). On average, CSHCN experienced 4.2 poor mental health days in the last month.

Prematurity and Disability

Advances in medicine and technology have reduced mortality of babies born at threshold of survival. In 1980, no Utah baby born at 23 weeks' gestation survived; in 1996, fifty percent of these very fragile babies survived. During this same time period, survival for babies born at 25 weeks' gestation improved from 50% to 90%. The incidence of babies born prematurely has remained constant over past 30 years. The incidence of long-term disability has remained high across the United States over time.

The Bureau of Children with Special Health Care Needs, Neonatal Follow-Up Program (NFP) staff compiled an outcome report on 545 extremely premature (<26 weeks' gestation) Utah babies born between 1986-2000. The average birth weight and hospital stay for these critically ill babies were 728 grams and 107 days respectively. The most commonly encountered disabilities include:

Condition of Extremely Premature Children (n=545) Seen by Utah NFP, 1986-2000	% Of NFP children
Children testing in the "mentally retarded" range (mental development/quotient ≤70)	31%
Children testing in the "educable" range (mental development/quotient 71-84)	15%
Children anticipated to need special education services	46%
Chronic lung disease	68%
Cerebral palsy	18%
Abnormal eye findings	33%
Blind in one or both eyes	4%
Sensorineural hearing loss	3%

The risk for long-term disability increases as gestational age decreases. Achievements in perinatal and neonatal medicine, pharmacology and technology have been a victory in terms of survival but often a disappointment in terms of long-term outcomes. Through periodic screening, early identification and timely intervention, the goal of the Neonatal Follow-Up Program is to maximize infant outcomes.

Utilization of Services

From the National CYSCHN Survey, 83.0% of families with CYSHCN reported delays or problems accessing dental care in the last twelve months. Of these, 59.2% stated they could not afford dental services and 14.4% experienced a health plan problem. Among all children with special health care needs who were age one or older, 85% had had a dental visit in the past 12 months. Only 52.9% of children in the youngest age group (age 1 to 5) had had a dental visit in the last year. Dental visits followed income levels with only 73.6% of children in households whose incomes were below poverty level having an annual dental visit compared to 92.4% for children in households with the highest incomes.

At the time of the survey, parents reported that 43.4% of children with special health care needs visited a specialist or specialty clinic, such as an orthopedist, neurologist, or a specialty clinic. Younger children were somewhat more likely to visit (52.1% of the birth to 5 age group). Children in households with incomes below poverty level were less likely to visit a specialist (36.4%).

Satisfaction with Care

From the National CSHCN Survey, almost all parents (93.4%) reported that they were "satisfied" or "very satisfied" with the health care received by their child or children with very little variation in the rate across various demographic subgroups. Only 48.9% of parents reported that doctors had spoken with the family about the child's future adult life plans. Most parents (82.4%) reported that they "usually" or "always" received the information they needed to make decisions about their child's health care needs. Most parents who responded to the Utah Child Health Survey, regardless of their race or ethnic background, reported that their doctor always showed respect for their customs, beliefs and language (87.5%).

At the heart of family satisfaction is the quality of family/professional partnerships at all levels of decision-making. However, meaningful sustained family/professional partnerships are challenging to establish and maintain. In the recently completed Utah Collaborative Medical Home Project (2004), only 58% of the families who participated reported collaborating with their doctor most of the time at post-test. Given the intensity of the project and the significant change efforts undertaken by the Medical Home practices, the high percentage of families who reported lack of collaboration with their doctor illustrates the complexity of the issue and the need for continued work in this area.

The challenges become even greater in establishing and maintaining family-professional partnerships when the family is not from the predominant culture. The summary from the Utah Health Status Survey on Ethnic Populations (Utah Health Status Survey on Ethnic Populations-Qualitative Component, Bureau of Surveillance and Analysis. 1997, Utah Department of Health.) found that "members of culturally diverse families (Asian-American, Latino, American Indian, African American, and Pacific Islander) indicated barriers in forming respectful partnerships with health care professionals and generally expressed the view that their own beliefs were not honored and that providers just focused on practicing 'Western Medicine'".

Issues for Children and Youth with Special Health Care Needs

In March 2005, as part of the larger MCH Needs Assessment, the Bureau of Children with Special Health Care Needs worked with the CSHCN Subcommittee to review data from previous state and national surveys as well as the recent statewide "Survey about Health Concerns for Utah Mothers and Children". As part of the 2005 Five Year Needs Assessment, the Division's "Survey about Health Concerns for Utah Mothers and Children" identified the following as the most important issues for children and youth with special health care needs: lack of physical activity; lack of respite care; depression and other mental health problems; transition to adult life and self-sufficiency; and, lack of childcare.

After numerous discussions and meetings, the CSHCN subcommittee prioritized the issues and needs for the Bureau to address over the next five years. The priority issues for Utah children and youth with special health care needs were: funding of health care, continued expansion of medical home, improvement of transition and vocational rehabilitation, provision of health care in rural Utah and ethnic and cultural health care issues.

Medical Home:

Only 10.1% of Utah parents reported that their child had no "usual provider" or that they rely on the emergency room for health care. A physician's office was the most common place reported for routine care (89.5%). A high percentage of respondents (67.7%) felt the doctors and other health care providers "always" or "frequently" respected their family's beliefs, customs, and language. The respondents always felt "satisfied" (51.1%) with getting the information they needed to make decisions about meeting their child's health care needs. The doctors made 66.0% of parents feel like partners in CSHCN care. (National CSHCN Survey)

Children with special health care needs often have more than one health care provider. In order for appropriate medical care to be delivered, it is necessary for a child's provider (Medical Home) to be aware of all the health care services that the child is receiving. Almost three-quarters of parents of children with special health care needs reported that the providers had a thorough understanding of all their child's health care services. However, almost one out of three (29.8%) reported that after going to a specialist or specialty clinic, their Medical Home provider (Medical Home) "usually spoke with them about what happened at the specialist visit in a way that they did not understand". (Utah CSHCN Survey)

Health Insurance Coverage

Children with special health care needs were more likely than other children to be covered by some type of health insurance; 5.2% of CSHCN were uninsured compared with 7.3% overall. The most common reasons given for lack of health insurance coverage for the child were "could not afford premium" and "lost Medicaid/CHIP eligibility". Children and youth with special health care needs who were more likely to be without health insurance coverage included children age 6 to 11 years (8.1%) and children living in households with incomes below the federal poverty level (19.9%). This finding is especially concerning, since in Utah almost all uninsured children living below 200% of the federal poverty level are eligible for Medicaid or the Children's Health Insurance Program (CHIP). In addition, only 48.9% of parents rated their health insurance plan as "adequate" at covering all the health care costs associated with their child with special health care needs. While most (58.6%) indicated that their annual out-of-pocket costs were less than $500, 2.2% reported annual expenses of $5,000 or more. (National CSHCN Survey)

Provider Issues:

From the "Physician Workforce: Ratios for Child Health 1998" in Division of Health Policy Research, American Academy of Pediatrics, Utah was ranked 48th among the 50 states and District of Columbia for the number of "Child Health MDs" per 100,000 children (55.7 vs. the national average of 85) and 40th for general pediatricians (40 vs. 57.5) per 100,000. Nearly 90% of the pediatric and family practice physicians are located in areas along the urban Wasatch Front. As with most large rural states, this heavy concentration of providers in urban areas creates a gap in pediatric medical services offered in the outlying communities. This disparity, while not unexpected, places an unusually high burden upon families of children with special health care needs in rural areas. These families must often travel long distances to seek needed specialty health care, which is not available in their respective communities. In fact, in Utah, access to specialty or subspecialty care for many children necessitates a drive of 3 to 7 hours. In some areas, the nearest pediatrician is 1 to 3 hours away. In many areas there are no pediatricians.

Access to pediatric subspecialists is not likely to improve despite the increasing population of Utah. The vast majority of growth will be along the Wasatch Front, leaving the rest of the state with still too few children to support subspecialists as important are the national workforce issues

affecting subspecialists. According to American Board of Pediatrics data the number of pediatricians intending to practice in a subspecialty decreased by 11% from 1988 to 1998, while the number intending to practice general pediatrics increased by 73%. Though demand will certainly increase as population grows, there may be insufficient pediatric subspecialists to meet the demand, which will leave general pediatricians and family physicians with an even greater responsibility for providing appropriate Medical Homes for children with special needs.

Despite the limitations posed by the distribution of health care services, very few (3.1%) families with children and youth with special health care needs in Utah reported dissatisfaction with the health care received by their child. Service coordination among providers and services was rated high by the large majority of Utah families with 75.1% reporting "very satisfied / somewhat satisfied". (National CSHCN Survey) The National Survey did not identify families as “rural” or “urban,” so it is unknown if rural families are more dissatisfied than urban families with access or organization of care. However, half (49.6%) of the families with CSHCN reported that they had no opportunity to talk with other CSHCN families and less than one in five (18.3%) reported receiving information or support from Family Voices or organizations for parents. (Utah CSHCN Survey)
Transition to Adulthood:

Over the past 20 years, health care advances have allowed CSHCN to live longer and more productive lives. The transition of these children into adult health care, work and independence has become a growing concern among providers, youth and parents alike. Utah’s population of young adults (18-22 years old) in 2004 is estimated to be 216,733 or 18.99% of Utah’s total population (Governor’s Office of Planning and Budget). If the 2001 CYSHCN Survey data for CSHCN prevalence are applied to these numbers, more than 23,500 young adults in Utah with disabilities will need transition to adult health care and access to multiple services to allow them to live as independently as possible.

Although the National CYSHCN Survey data were not deemed reliable for the core component of “transition”, other sources of local and state data provide the ability to extrapolate information about the needs and gaps in services for these children and their families. The National CYSCHN survey reports that more than two out of five parents of youth with special health care reported that their health care providers had not communicated with them about plans for their child's future adult life. Another source, the Parent Advocacy Coalition for Educational Rights (PACER) Center's Technical Assistance about Transition and the Rehabilitation Act (TATRA), reports from a national study that families identified the need for: 1) family-friendly materials available in different languages and at appropriate reading levels; 2) information on best practices in collaboration across agencies and communities and family success stories; 3) coordinated, individualized, and future-oriented planning and services to students in high school; 4) resources, programs and opportunities for students after they graduate from high school; 5) support for employment, post-secondary education, and residential alternatives; and 6) opportunities for students to participate in challenging career development or experience a variety of occupations.

In another national study, “Transition for Youth with Chronic Conditions: Primary Care Physicians’ Approaches”, four significant barriers to successful transition of adolescents were identified by physician respondents: 1) difficulty in identifying adult primary care providers; 2) adolescent resistance to transitioning to adult provider; 3) parents’ resistance to transitioning their child to an adult provider; and, 4) lack of institutional support for making the transition to adult care, including planning time, resources and personnel. Adolescent and parent resistance were problems that could be overcome, but difficulty in identifying adult providers was the critical barrier identified most consistently by respondents in the study.

Further expanding this issue, Utah physicians report a number of barriers in meeting the full range of challenges posed by this population. In 2002, the Utah Medical Home Collaborative Project conducted a focus group on the subject of transition to adult care for youth with special health care needs. The participants identified the following challenges in supporting transition of young adult with special needs: 1) lack of continuity of care between pediatric provider of care and adult provider of care, including adequate referral and notification of transfer as well as transfer of medical records; 2) lack of resources for older children and lack of knowledge about resources; 3) lack of internists trained in rare and complex conditions or in developmental delays; 4) inadequate reimbursement for efforts; and, 5) inadequate insurance for specialty care, especially mental health.

Health Service Gaps for Children and Youth with Special Health Care Needs

Access to Health Care Services

Almost 18% of CSHCN had problems getting medical care, 15.1% of CSHCN had problems getting dental care, and 7.3% had problems getting mental health care (Utah CSHCN Survey). The most common barrier parents cited as a reason for having a problem with access to care was "could not afford services", cited by 20.9% of parents. Parents of older children and those with lower incomes were more likely to report that cost had prevented or delayed services for their child. More than one out of every eight (13.7%) families with CSHCN reported delays or problems accessing medical care in the last twelve months. The primary reason given was that they could not afford the medical, dental, eye care, or other health services.

Health Insurance

More than 80% of families with CSHCN (83%) reported delays or problems accessing dental care in the last twelve months. The primary reasons given were that they could not afford dental services or there was a problem with their insurance. Almost one-third of parents (30.1%) of CSHCN, reported needing (not receiving) mental health care or counseling related to CSHCN medical, behavioral, or other health related issue in the past 12 months. (National CSHCN Survey)

Transition to Adulthood

As documented in the previous section, there are many service gaps for children and youth with special health care needs as they transition to adult health life.

Mental Health

According to the National Survey, approximately 42% of children and youth with special health care needs were reported to have "one or more days" in which their mental health was "not good" (including stress, depression, and problems with emotions). On average, children and youth with special health care needs experienced 4.2 "poor" mental health days in the prior month. According to the survey, access to counseling was compromised: 30.1% of families reported needing and not receiving mental health care or counseling related to their child's medical, behavioral, or other health related issues. Anecdotally, families that have low income, live in rural areas and are non-English speaking have even less access to mental health services. Public mental health services in Utah are focused mainly on the provision of care to adults and children with chronic or acute/severe psychiatric conditions and less focused on early identification and prevention of mental health concerns. Also, families can usually only access the public mental health system if they have Medicaid or health insurance.

Medical Home

Although there are significant and ongoing efforts regarding expansion of Medical Home information and support for the already established Medical Homes, there is still much to do, as documented through the National CSHCN survey results. The CSHCN Bureau staff believes strongly that the Utah Medical Home initiative is the cornerstone for the accomplishment of the other five National CSHCN outcomes.

Strengths and Weaknesses of the System

The Bureau of Children with Special Health Care Needs has been fortunate to receive the President's New Freedom Initiative: State Implementation Grant for Integrated Community Systems for Children and Youth with Special Health Care Needs. This three-year grant enhances our capacity to expand and improve the system of care for children and youth with special health care needs, particularly in the areas of transition, family involvement and medical home. The already established and strong collaboration with the University of Utah Department of Pediatrics and Utah State University, Center for Persons with Disabilities, as well as Utah Family Voices and Medicaid will help to ensure the success of this project.

Issues surrounding access to mental health services continue to be problematic. Utah's Department of Human Services, Division of Mental Health and Substance Abuse has recently received a significant five-year grant to evaluate and establish the infrastructure for a statewide system of care for children and youth with mental illness. Several members of the Bureau of Children with Special Health Care Needs are actively involved on three of the subcommittees for this grant. In addition, the Title V Director is on the steering committee of the grant and chairs one of the subcommittees. Staff in the MCH Bureau is also involved in this effort.

When a child with special health care needs enrolls in WIC, the clinic counselors identify counseling guidelines related to the child's disorder in order to provide specialized education for the parents. WIC staff also ensures that the child has a medical specialty provider. The Utah WIC Program provides any specialty formula medically required for infants or young children with special needs, a priority service provided by the Utah WIC Program although it is not required as part of the USDA minimum standard.

The Bureau of CSHCN is very fortunate to enjoy an excellent working relationship with the Utah Chapter of Family Voices, as well as with the Utah Parent Information and Training Center. The Bureau is involved with the new Family-to-Family Information Center. Not only does the Bureau support the Center financially, but Bureau staff is also on the Advisory Board for the Center. In addition, the Bureau is working with Family Voices as they complete their technical assistance focus groups on health insurance information needed by Utah families. Ultimately this information will be used to develop insurance information modules on the Utah MedHome Portal website.

Over the past 5 years, numerous successful public and private projects have expanded and improved the service system for Utah children and youth with special health care needs and families at both the state and community level, including the Utah Leadership Education in Neurodevelopmental Disabilities grant, the Utah Registry for Autism and Developmental Delay grant, the Newborn Hearing Screening grants and Birth Defect Surveillance grants. Through these grants and many other collaborative efforts, the Bureau enjoys a strong working relationship with the majority of key players in service provision and advocacy for children and youth with special health care needs in our community.

Utah continues to have very generous and broad Medicaid coverage for children. Children enrolled in Medicaid generally receive a more comprehensive service package through their Medicaid benefits than children covered by private insurance or CHIP. Although CHIP benefits are not as generous as Medicaid, it is beneficial for the many children with mild chronic health conditions. Under the Governor's directive and supervision the Department of Health hosted a full day "Summit on the Uninsured in Utah". Over 200 Utah leaders and legislators attended this summit, which will result in the establishment of work groups given the task of evaluating potential strategies for insuring all Utah citizens.

The Division of Community and Family Health Services houses the newly established Center for Multicultural Health. This office was recently awarded an addition $50,000 per year by the state legislature, to evaluate health disparities and solutions in our state. The manager of the Center is an active participant in the CSHCN/MCH Advisory Committee and the CSHCN subcommittee. He has been involved in the CSHCN need assessment efforts. In addition, as previously discussed, the Bureau and Division will be collaborators in the Utah State University grant to evaluate the needs of Hispanic people with disabilities.

The CSHCN Bureau will continue to address access to care in rural areas through ongoing itinerant clinics and satellite case management through local health department. We will continue to support and develop the capacity for local providers to care for children and youth with special health care needs through the Medical Home initiatives. The Bureau is involved with the "Utah Clicks" project, which will improve access for all families to appropriate resources, specifically Presumptive Eligibility, Medicaid, CHIP, Early Intervention, and CSHCN.

Utah is also fortunate to have excellent health care resources for children, including University of Utah Health Sciences Center, Primary Childrens Medical Center and Shriners. In addition, as has been previously documented, the CSHCN Bureau enjoys an excellent working relationship with Utah State University's Center for People with Disabilities, the Utah Center of Excellence for People with Developmental Disabilities.

IV. MCH Program Capacity by Pyramid Levels

Direct Health Care Services and Enabling Services

Needs assessment for these two levels of the pyramid of services were combined into one section as outlined in the guidance.

Priority state concerns regarding access to health care and health-related services

One component of the 2006 Needs Assessment was the Division statewide "Survey About Health Concerns For Utah Mothers and Children", which surveyed individuals representing Department programs, other state agencies with whom the Department partners, community-based agencies, advocacy organizations and parents regarding their perceptions of needs for mothers, children, and children and youth with special health care needs and their families in the state. The results of the survey, along with key data, were reviewed to determine the state's priorities for the next five years. These priorities include issues related to access to care and health related services.

The needs identified in order of importance under each category, were:

Mothers and infants

- Unplanned pregnancies
- Obesity
- Depression or other mental health problems

Closely spaced pregnancies
Poor nutrition during pregnancy

Children
Lack of physical activity
Obesity
After school supervision
Teen pregnancy
Depression or other mental health problems

Children and Youth with Special Health Care Needs
Lack of physical activity
Lack of respite care
Depression or other mental health problems
Transition to adult life and self-sufficiency
Lack of childcare

Health Care Services or Systems
Dental insurance
Obtaining financial help for health care
Health insurance
Services not covered by insurance
Dental care

Priority concerns for women of reproductive age include the percentage of women who enter prenatal care after the first trimester, lack of financial coverage for prenatal care for undocumented Hispanic women, availability of family planning services for low-income women and mental health services for all women of reproductive age.

Priority concerns for children include lack of physical activity; increasing percentages of children who are at-risk for overweight and overweight; after school supervision; teen pregnancy; and, depression or other mental health problems, especially Utah's high youth suicide rate.

Priority concerns for children and youth with special health care needs include: lack of physical activity; lack of respite care; depression or other mental health problems; transition to adult life and self-sufficiency; and, lack of childcare. Included priorities relate to ethnic and cultural needs and medical home.

Health care services or systems priorities include: dental insurance; obtaining financial help for health care; health insurance; services not covered by insurance; and dental care. These issues have been reviewed and considered by the MCH Advisory Committee and its subcommittees. The Subcommittees provided recommendations to state Title V leadership to review and determine the priorities and state performance measures for the next five years.

Other concerns:

Funding for family planning services for low-income women in Utah is problematic. Many women lose their Medicaid coverage approximately 60 days following delivery and are then without coverage to obtain effective contraception. Utah has experienced an influx of Spanish-speaking immigrants many of whom are of undocumented status. From 1999 to 2003, the number of births to Hispanic women rose from 11.8% to 14.2% of all births. According to the 2001 Utah Health Status Survey, 25.8% of Hispanics had no health insurance compared to 7.2% of non-Hispanic residents who were uninsured. Although data on availability of mental health care

services for women of reproductive ages have not yet been compiled, anecdotal reports indicate that this is a problematic area of access. PRAMS data indicated that postpartum depression is a problem in Utah with approximately 25% of Utah women reporting moderate to severe depression.

Another priority concern for women of reproductive age is geographic availability of prenatal and family planning services for rural and frontier residents. According to Health Professional Shortage Area surveys conducted between 2000 and 2004, there are areas in Utah with high ratios of women of childbearing age to providers, resulting in limited access to a prenatal provider in their area**.** Women in rural communities may have to travel many miles to a provider and/or hospital. More than half of the counties (16 out of 29) are without any obstetrician-gynecologist with several counties reporting as few as 1 provider to 10,000 women of childbearing age.

According to the 2003 Utah Health Status Survey, an estimated 7.3% or 54,500 of Utah children were without health insurance. While budget limitations for the Children's Health Insurance Program (CHIP) have been a challenge, improving access to health care through health insurance is a priority for the Governor and the Utah Department of Health. Collaborative efforts within the Department, between Title V and Medicaid, as well as efforts with other organizations to enroll children, keep them enrolled, and increase the funding for the program to serve more children have been a priority. With the additional state funding for CHIP, the expectation is that the enrollment capacity will be adequate.

Results from the Utah Department of Health 2003 Health Status Survey indicate that 28.1% of children did not receive a routine medical check-up in the previous twelve months. More than 8% of children were unable to access needed medical, dental, or mental health care.

Access to dental care is a priority concern, especially for Utah children, including those with special needs. Dentists willing to take Medicaid-enrolled children are becoming more of a problem than ever due to low dental reimbursement rates. In addition, the misperception that oral health is not related to overall general health remains a challenge to overcome.

Being uninsured, underinsured or uninsurable are three critical barriers to accessing health care for women of childbearing ages and children, but especially for children and youth with special health care needs. Issues, such as living in rural areas, low socioeconomic status, personal beliefs about health care, primary language, or ethnicity affect access to health care. The low or non-existent providers in Utah especially in rural areas compounds access to care and the paucity of available mental health and dental services are seen as an issue for women of childbearing ages, children and youth, especially for those with special health care needs. Direct and enabling services for children and youth with special health care needs are available through many private providers and Utah's tertiary care centers along the Wasatch Front, but the same is not true for the less populated areas. Certain types of specialists or services continue to be difficult for families living in these areas to access, including high-risk obstetrical care, home health nursing, dental, genetics, orthopedics, neurology, multi-disciplinary evaluation services for developmental delay and pediatric mental health. Certain preventive and support services are especially difficult for families of children and youth with special needs to access, such as dental services, physical, occupational, speech or language therapies, respite care, vocational rehabilitation and transition to adult health care. Problems with access to care are compounded by the increasing complexity of insurance coverage.

Financial access

According to the 2004 Utah Health Status Survey, the percentage of Utahns with no health insurance had increased since 2001. Those aged 18 to 34 years were most likely to report no health insurance, with males more likely than females to lack health insurance. In 2004 15.5% of Utah women 18-34 years of age had no insurance. The 2004 Utah Health Status Survey indicates that 8.2% of children birth to 17 years of age representing more than 63,000 children was estimated to be without any type of health care coverage. CSHCN are more likely to be insured than other children with 5.2% of CSHCN not having insurance (according to National CSHCN Survey).

Eligibility for Utah's Prenatal Medicaid program has not been increased from the 133% of the federal poverty level (FPL) as determined in 1990 and continues to require an asset test for enrollment. As a result, many women and their families, best categorized as working poor, are ineligible for health care coverage, making it difficult for them to access health care, especially prenatal and family planning services. In April of 2004, the Presumptive Eligibility application was revised to more closely reflect Medicaid guidelines. These revisions resulted in a more stringent citizenship question requiring applicants to have permanent residency status. The changes also more closely defined household membership. Utah's Primary Care Network (PCN) Waiver was approved by DHHS to enable the state to provide coverage for an additional 25,000 individuals for a reduced package of primary care services. However, PCN has reached enrollment capacity and applications are currently only accepted during designated enrollment periods. Additionally, no prenatal coverage is available through the program, undocumented women are not eligible for coverage under PCN and anecdotal information indicates that the fifty-dollar enrollment fee may pose a barrier for some women. Medicaid's current eligibility level for children birth -5 years of age is 133% FPL and 100% FPL for children 6-18 years of age. The Utah CHIP eligibility level is 200% FPL for children from birth to age 18 years.

Access to low cost prenatal care and family planning through community health centers and local health departments has been problematic in many areas of the state, especially in the rural areas without community health centers. Although sliding fee schedules are available, the demand for low cost health care often exceeds capacity, especially for women of undocumented citizenship status.

Financial barriers to family planning services are significant. The state does not allocate any state dollars to family planning services with exception of the state match for Medicaid services. State legislation mandates state agencies and political subdivisions of the state to obtain parental consent prior to provision of family planning information or services to unmarried minors. As a result, many adolescents desiring family planning services through the low cost clinics available via local health departments are unable to access them. The Alan Guttmacher Institute has estimated that there are approximately 147,000 women ages 13-44 years in Utah in need of low-cost family planning services in Utah. Approximately 9,000 women who qualify for Medicaid for prenatal care each year lose their Prenatal Medicaid eligibility approximately sixty days after delivery, leaving them without a third party payer for family planning. Without access to long-term family planning, adequate spacing of pregnancies for optimal maternal and child health outcomes is very difficult for many of these women. Although local health departments, community health centers and clinics operated by Planned Parenthood Association of Utah, the state's Title X grantee, offer family planning services on a sliding fee scale, they all are limited in their ability to provide services to low-income women to meet the high demand for these services.

Over the past few years, several local health districts have been denied discounted oral contraceptives by the pharmaceutical companies on the grounds that they do not meet the

qualifications to be covered entities described in Section 340B(a) of the Public Health Service Act. Local health departments in Utah do not receive Title X funding, 330 funding or any other funding sources listed in the act as eligible for this vital coverage. Title V Maternal and Child Health Block Grant funds are not among those qualifying for 340B Program participation. Without 340B discounts, women in these local health districts have to pay retail for their oral contraceptives making purchase of contraceptives impossible for many. As a result, some local health departments have formed purchasing alliances that enable them to purchase contraceptives at discounted rates. However, as more of the health districts lose the 340B discount, provision of oral contraceptives will become more limited. Additionally, several local health departments have removed Depo-Provera from their formularies due to prohibitive retail costs due to loss of the discount purchasing.

For all children in Utah, access to care continues to be a challenge. Results from the Utah 2003 Health Status Survey indicate that 28.1% of children did not receive a routine medical check-up in the previous twelve months. More than 8% of children were unable to access needed medical, dental, or mental health care.

The Utah Children's Health Insurance Program (CHIP), implemented in August 1998, is a state-developed health coverage assistance program for children who do not have other health insurance and who meet the program's eligibility criteria. To be eligible for Utah's CHIP Program, a child must be age 18 or younger, not covered by an insurance plan and not eligible for Medicaid. The family's income must be below 200% of the federal poverty level (FPL) and above the Medicaid's income standard of 133% of the FPL for children birth through 5 and 100% of the FPL for children ages six through 18. Due to budget limitations over the past few years, CHIP enrollment was limited to one to two week open enrollment periods once or twice a year in order to stay within the allocated budget. Enrollment data for August 2003 indicate that approximately 28,000 children were enrolled in CHIP. Department of Health estimates indicated that approximately 53,000 might have been eligible for CHIP in 2003.

Covering Kids and Families Utah, a Robert Wood Johnson Foundation Partnership three-year grant project, is managed under the guidance of a statewide coalition and state-level coordinator. It has been implemented with the support of Covering Kids, a national access health initiative for low income, uninsured children. Voices for Utah Children, a statewide child advocacy organization, is leading the project that focuses on enrollment, retention and simplification of the application processes for CHIP and Medicaid for children up to age 19. Out-stationed Medicaid eligibility workers, a shortened enrollment form and other efforts have helped increase accessibility to enrollment and coverage for families. These efforts, supported by the Utah Department of Health, have also increased cooperation and collaboration among health care providers and state programs. A new Coalition strategy includes exploring matching children enrolled in free and reduced school-lunch programs in specific areas with CHIP enrollment information to better target those who might be eligible for CHIP during open enrollment periods.

The Medicaid and CHIP Programs in Utah have faced several challenges, mostly related to budget capacity and need for services. Due to budgetary concerns, CHIP imposed co-payments for health services as well as premiums in January 2002. Although these requirements are compliant with federal regulations, they may have resulted in a higher number of disenrolled children from approximately 500 per month before the changes to more than 1000 per month after the changes. Enrolled families tend to drift in and out of the programs often depending on changes in income levels or in health status. Enrollment may lapse during periods of health with reapplication in time of medical need. In an effort to address enrollment challenges, CHIP made rule changes in 2004 that allowed children being disenrolled from Medicaid due to income and age limitations to be

enrolled in CHIP, and that allowed newborn or adopted children (if they met the eligibility requirements) of families enrolled in CHIP to be enrolled without having to wait for the next open-enrollment period. In 2004, rule changes allowed families that were delinquent in premium payments to make back payments and re-enroll within a one-year time period.

Some Hispanic parents who are legal residents or of undocumented citizenship status may not enroll their children in Medicaid or CHIP for fear of negatively impacting their citizenship application, being reported to the U.S. Citizenship and Immigration Services, or possible deportation. The grant-funded Covering Kids and Families Coalition includes members of projects working with the Hispanic community. Outreach from the Coalition and Department is being conducted to reach this community through Spanish-language print materials, radio and television ads, and newspaper articles.

It is hoped that the child health initiatives (CHIP and Medicaid) will help ease the financial burden of health care for low-income children and their families and increase access to care. It is also hoped that families, once enrolled, will utilize the system in a way that emphasizes preventive health care and decreases the use of emergency rooms and insta-care facilities as stopgap measures of health care. However, for families with children with special needs, many needs services are not covered by private insurance or CHIP. Financial barriers continue to exist for families and children whose condition and/or services are not covered by third party payers or managed care organizations (e.g., pre-existing conditions, therapy, orthodontia, dental and surgical exclusions). Limited provider panels offered through managed health care plans reduce the accessibility to qualified specialty care available for children. Utah CHIP has improved basic medical coverage for uninsured children but specialty services are not covered. Though Utah's CHIP provides access to routine health care, it was not designed to provide adequate coverage for the special needs populations, putting them at risk of being underinsured. Family advocate groups are generating support for the Family Opportunity Act, which would allow broader financial eligibility to Medicaid for children with disabilities.

In addition, access to dental services is problematic for many children. Children who would otherwise be eligible for CHIP have no dental coverage because they have health insurance without dental coverage (estimated to be about 19,000 by the 2000 Utah Child Health Survey). As a result, they are not able to easily access dental health services unless their parents are able to pay out of pocket for the services.

To improve access to services, Medicaid developed the Early Childhood Targeted Case Management Service for Medicaid-eligible infants and young children provided by public health nurses to assess the young child's health needs and referral to a medical home and other needed health care and social services. Public health nurse staffing shortages and challenges in providing matching funds have prevented Medicaid's Early Childhood Targeted Case Management Service from reaching its full potential.

Access to immunizations may be difficult for children who are underinsured, for example, children whose family income is between 100 and 200 percent of the federal poverty level who would qualify for CHIP except for the fact that they have some medical insurance. The State Immunization Program's Vaccine for Children (VFC) Program is available for children who are on Medicaid, uninsured, underinsured, or of American Indian/Alaska Native heritage. VFC provides free publicly funded vaccine to enrolled providers; however, not all Medicaid providers are enrolled in the VFC program. Local health departments charge an administration fee for immunizations between $5.00 - $15.00, which can be waived for families unable to pay.

Many low-income families are not able to afford medical nutrition therapy due to lack of insurance coverage or funds to pay for these services out of pocket. The Utah WIC Program provides comprehensive nutritional services, along with needed food supplements to eligible women, infants and children. However, with Utah's rising birth rate and static funding levels, WIC has been challenged to maintain services to enrollees and many districts are experiencing increases in caseload. Because the current WIC funding formula is not adequate to meet the demand and need for WIC Services for all eligible women, infants and children in the state, the Program is not able to actively reach out to all eligible for services due to funding shortfalls.

According to the National CSCHN Survey, Utah children with special health care needs were more likely than other children to be covered by some type of health insurance, with 5.2% of CSHCN being uninsured compared with 7.3% overall. The most common reasons given for the child lacking health insurance coverage were "could not afford premium" and "lost Medicaid/CHIP eligibility". CSHCN who were more likely to be without health insurance coverage included children ages 6 to 11 (8.1%) and children living in households with incomes below the federal poverty level (19.9%). Almost all uninsured children living below 200% of the federal poverty level are eligible for Medicaid or the Children's Health Insurance Program (CHIP), therefore one might surmise that outreach efforts to this population need to be increased.

Only 48.9% of parents rated their health insurance plan as "adequate" in covering all the health care costs associated with their child with special health care needs. Insurances and CHIP offer some habilitative services for a child, such as physical, occupational or speech/language therapies, but the number of visits is so limited that the needs of children with very critical needs may not be covered. Special education can augment these services, but therapies at school are still often inadequate.

While most families (58.6%) indicated that their annual out-of-pocket costs were less than $500, 2.2% reported annual expenses of $5,000 or more. The most common reason that parents reported for having a problem with access to medical, dental or other types of care was "could not afford services" cited by 20.9% of parents. Parents of older children and those with lower incomes were more likely to report that cost had prevented or delayed getting services for their child.

Utah children with Medicaid enjoy a relatively generous Medicaid package. Medicaid does not, however, extend to those children with special health care needs or their families who are of undocumented citizenship status unless they have a life-threatening condition. Children who are eligible for SSI disability benefits are also eligible to apply for Medicaid coverage, although they must complete a separate application. Although more children are able to access care through Medicaid outreach and the availability of CHIP, some children still remain uninsured either due to financial factors or inability of the parents to follow through with the application process.

Though Utah's CHIP Program provides access to routine health care, it was not designed to provide adequate coverage for the special needs populations, putting them at risk of being underinsured. Low-income children and youth in Utah with special health care needs are often eligible for Medicaid through the "disability" category that gives the child access to relatively more extensive health coverage than CHIP.

Utah Medicaid offers a number of different options, which are designed to maximize financing of care through Medicaid. The Bureau of CSHCN has negotiated several different types of reimbursement options with Medicaid, such as reimbursement for specific clinical and case management services provided through a Medicaid Administrative Case Management contract.

The Baby Watch/Early Intervention Program (BWEIP) has negotiated Medicaid reimbursement for services for children between the ages of birth to three years. Approximately

30% of children in BWEIP are Medicaid eligible. Covered services include: case management, individual physical, occupational and speech therapy, nursing and referral to other resources in the community. Medicaid also reimburses for "child find" activities and general administration of the program for Medicaid eligible children.

Additionally, the CSHCN Bureau receives funding to administer the Travis C. Waiver for Technology Dependent Children, a Medicaid home and community-based waiver program. Through this waiver, CSHCN Bureau nurses provide intensive case management for children and families with multiple and complex needs as they care for a medically fragile child in their home. The waiver also provides Medicaid eligibility for these children by waiving the family financial eligibility requirement. Services beyond the regular Medicaid program that are available for children on the waiver program include: case management, skilled nursing respite, expressive therapy, family counseling visits, respiratory therapy, feeding therapy and nutritional services.

The Technology Dependent Waiver is one of two waiver programs in Utah, which allows families to access Medicaid for their children. The other waiver is the DD/MR Home and Community Based Waiver administered by the Division of Health Care Financing through contract with the Division of Services to People with Disabilities (DSPD). As of March 2005, this waiver was serving 919 individuals under the age of 18, but has a long waiting list due to inadequate state funding. This waiver provides services beyond the regular Medicaid program such as case management, residential and day treatment, supported employment, family support and companion services.

The School Age and Specialty Service (SASS) Program transition specialist provides training, consultation, and support to CSHCN Bureau staff and community partners in the area of adolescent and young adult transition services. These services include planning for financing ongoing health care and transitioning to adult health services. SASS collaborates with other private organizations (i.e., Shriners Hospital for Children) in presenting "transition fairs", where service providers can offer information on health care for youth becoming adults, Medicaid and SSI eligibility, managed care, independent living, vocational rehabilitation, advocacy, rehabilitation, education and employment. SASS staff members work with the community-based programs to identify possible participants from their communities. CSHCN Bureau staff in clinical and community-based, rural programs receive assistance and education in the process of supporting families throughout the SSI application. Training is provided in identifying potential candidates for SSI participation and increasing successful referrals of children. SASS maintains a statewide database of potential SSI eligible children age 16 and under.

Availability of care

Services for the three populations served through Title V are offered in a variety of settings: medical homes/private provider offices; public providers in local health departments, community health centers, a clinic for the homeless, migrant health clinics; itinerant clinics offered through the CSHCN Bureau to rural communities without specialty providers; and specialty settings, such as the University of Utah Health Sciences Center, Primary Children's Medical Center, Shriners Hospital for Children, and the other Level III centers for perinatal care. These centers of excellence are able to provide centralized specialty and subspecialty services to high-risk pregnant women and children who have numerous disabling conditions, such as asthma, hemophilia, cystic fibrosis, diabetes, Down syndrome, cancer and orthopedic disorders. Although this centralization allows for better coordination of care because there are fewer providers, it also presents a problem of service delivery to high-risk pregnant women, high-risk infants, and special needs children in rural Utah.

Local health departments (LHDs) and community health centers (CHCs) provide the local systems of care throughout the state for the MCH population as well as adults. The 12 autonomous local health departments (LHDs) have their own unique governance and array of services. Most local health departments are multi-county districts covering large geographic areas. The Utah Department of Health contracts with each of the health departments to provide various services and core public health functions on a local level, including maternal and child health block grant funds, immunization infrastructure, WIC administration, tobacco prevention, prevention block grant funds, etc. Each local health department prioritizes its use of the Title V funds. The Department of Health is responsible for oversight of the state and federal funds that are distributed to the local health departments through contracts.

The Utah Department of Health also has contracts with community health centers for maternal and child health services, mainly for immunization infrastructure. The Division does provide a small amount of funding from the MCH Block Grant to fund prenatal services for uninsured women in the Salt Lake Community Health Centers, Inc. system.

The 10 community health centers and the Wasatch Homeless Clinic provide primary care to underinsured and uninsured MCH populations. Four of these community health centers are located in rural areas of the state, one of which is operated in conjunction with a local health department. Three migrant farm worker clinics are co-located with Wasatch Front community health centers and a fourth clinic is located in Brigham City. Unfortunately, many of Utah's Hispanic workers, especially along the Wasatch Front, are not engaged in farm work and therefore do not qualify for these services.

The community health centers in Utah in 2003 provided services to 3% of the state's total population and 4% of children 18 and under in the state. They provide services to 16% of the population under 100% of the poverty level, 9% of the population under 200% of the poverty level, 16% of the state's uninsured population and 24% of the low-income, uninsured population. OF the individuals who receive services at a CHC in Utah, 61% are uninsured, 15% are Medicaid enrolled, 68% are at or under 100% of the FPL, 93% are under 200% of the FPL. More than half of the clinic population is Hispanic or Latino (52% vs. 10% in state), 7% American Indian/Alaskan Native (versus 1% in state), and 38% white (compared to 84% in state). In 2003, more than 80,000 individuals were seen in CHC clinics, including 31% being women of childbearing ages, and 41% of those seen preferring a language other than English.

According to the National Association of Community Health Centers, Inc. more than 450,000 Utahns are without access to a primary care provider. Utah has a higher percentage of residents without access to a primary care provider than nationally – 19% versus 12%.

Most local health districts no longer provide primary care services for MCH populations. Services available through local health departments (LHD) vary depending on priorities as established by the health district. For example, prenatal services are no longer available through LHDs, although two districts provide clinic space and support staff for prenatal services provided by University of Utah Health Sciences Center providers. Family planning services are available only through mid-level practitioners in several health district clinics. The shift away from direct services provided by local health departments reflects the changing public health system to focus more on health promotion and prevention services.

During FY2004, local health departments provided services to more than 71,000 women and children, of whom 21% were Hispanic, 1.4% were American Indian, 0.5% were Black, and 3.8% were Asian or Pacific Islander. More than 11,400 women were seen for pregnancy related or family planning services, of which 30% were Hispanic. More than 40% of women seen for

pregnancy-related services reported no insurance and 55% were on Medicaid. Of women seen for family planning services, almost 90% (89.8%) reported no insurance, with only 1.8% on Medicaid. Local health departments provided services to almost 58,000 children of whom 20% were Hispanic; 10% had no insurance and 51% were on Medicaid or CHIP. Local health departments provided services to 1819 children with special health care needs.

The public health system in Utah is hampered in providing services to all in need due to funding shortages, staffing shortages, etc. Utah is faced with a growing population of families without insurance, especially those of undocumented citizenship status, placing a stress on a health care system with limited resources. Local health districts and community health centers in the state have been forced to place limits on the number of individuals served due to limited resources. Limited resources also preclude hiring additional public health nurses to provide more in-depth services to the maternal and child populations of the state, such as care coordination, home visiting services, and grief support to families that experience infant deaths. In addition, the limited numbers of Spanish-speaking public health nurses employed by the local health departments is a barrier to serving more Spanish-only speaking families. Local health departments have worked hard to bring on Spanish-speaking staff however; they are limited in this area due to budget constraints and limited numbers of individuals who are able to fill the positions when available. . Unfortunately, in one health department a Spanish-speaking male nurse resigned after facing cultural challenges regarding his gender and lack of public awareness about the program.

Eight of the twelve local health departments offer well child services to infants and children. Whenever necessary, referrals are made to providers and/or clinics within the community for follow-up of identified health concerns, and the local health departments strive to assist families in identifying primary health care providers for their children. The local health departments are encouraged to promote medical home for children they see in their clinics.

The Prenatal - 5 Nurse Home Visiting Program is available in eleven of the twelve local health departments. Home visitation is an intervention to assist families in gaining access to information and services that support and strengthen their capacity to meet their own needs and those of their children. The Utah program, targeted toward at-risk pregnant women and children from birth to 5 years of age and their families, is directly managed at the local health department (LHD) level and staffed by their public health nurses. Home visits are conducted to assess child and family strengths and needs related to overall health and well being, and to provide anticipatory guidance, information, assistance, and/or referral to assist families in meeting identified needs. Local health department participation in this MCH Block grant-supported program component, through contract, is voluntary. Contract funding to support the program is limited and is clearly not sufficient to fully support the level of staffing needed for local programs to provide services to all in need. Several local health departments supplement MCH Block grant dollars with additional local or private dollars, which they have been successful in garnering through other funding sources. In areas with limited funding and severe nursing shortages, participation is usually reserved for at-risk pregnant women and young children determined by the public health nurse to have the greatest need for the services. One local health department has experienced severe nursing shortages and has been unable to provide services for a significant period of time. Technical assistance, consultation, development of guidelines and standards, contract and program development and monitoring, data collection and analysis, and program evaluation are coordinated at the state level by the Child Health Nurse Consultant and the Child Adolescent and School Health Program Manager.

Following a SIDS or asphyxiation death, each of the twelve local health departments assigns public health nurses to provide home visits for families who have experienced an infant death by providing support and collecting important information on various factors known to impact SIDS, such as the baby's position at the time of death.

Mental health services are available privately and through Medicaid Prepaid Mental Health Plans throughout Utah. However, services are not adequate for women of reproductive age and children, especially in rural Utah. Collaborative efforts involving multiple agencies are underway to improve the mental health services for women and children in the state. Mental health services for Medicaid recipients are delivered primarily through community mental health centers. The community mental health centers coordinate with other providers of children's services through case management and other mechanisms, e.g., regular meetings with other child-serving agencies, etc.

Community-based dental clinics are available in some parts of the state, which include: three community health center (CHC) dental clinics in Salt Lake County; six Family Plan Dental Clinics (Medicaid only) in Salt Lake City, Ogden, Layton, Provo, and St. George; three local health department dental clinics in Vernal, Heber and Tooele; five donated dental services clinics in Salt Lake City, Ogden, Wendover, St. George and Logan; and three school and community-based clinics (preventive services only) in Salt Lake City and Ogden. Funding has been requested to establish dental clinics in community health centers in Price. CHC dental clinics have been established in Ogden, Green River and Bear Lake. None of the community-based centers provides specialty care, such as treatment under general anesthesia or orthodontic treatment. Primary Childrens Medical Center provides some services for children requiring extensive dental care, especially those cases requiring anesthesia.

In Utah, 15% of Medicaid-covered children and adults receive dental services from six Family Dental Plan Clinics, which are Medicaid-only clinics managed by the Division of Health Care Financing/Medicaid, located in Salt Lake City, Ogden, Layton Provo, and St. George. Additionally, there is one local health department Medicaid-only dental clinic in Vernal. Seven community health center dental clinics are also available to serve adults and children who are covered with Medicaid or can pay on a sliding fee scale. Three of these clinics are located in Salt Lake County.

Although Medicaid dental benefits were reduced to emergency treatment only for adults in 2003, full dental benefits are covered for pregnant women on Medicaid. Unfortunately, the change in adult dental coverage created confusion about the dental benefits that were still available for pregnant Medicaid participants. Access to a dentist willing to provide services for Medicaid participants is difficult for many in the state due to low provider reimbursement rates, which has lead to provider unwillingness to serve the Medicaid population.

People with disabilities find it especially difficult to access oral health care for several reasons including: most individuals with disabilities are Medicaid recipients; many dentists are reluctant and/or not trained to treat people with disabilities in the traditional office setting; many dentists are not willing and/or do not have the appropriate anesthesia permit to see individuals with severe disabilities in a hospital or surgical care center; and, few tertiary care facilities in rural Utah where dental treatment can be conducted for people with severe disabilities.

CSHCN provides direct services in their Salt Lake City office for three specific populations: follow-up of premature infants, developmentally delayed preschool age children, and developmentally or behaviorally disordered school age children and youth.

The Bureau of Children with Special Health Care Needs in collaboration with the pediatric tertiary care centers continues to provide direct and enabling services to children with special needs who are unable to access services through other sources. These direct services include rural multi-disciplinary pediatric clinics; early intervention services in 12 rural and 7 urban centers; newborn follow-up multi-disciplinary clinics for newborn ICU graduates in Salt Lake, Provo and Ogden; and two behavioral and developmental clinics in Salt Lake City through the Bureau's Adaptive Behavior and Learning Environment (ABLE) and the Child Development Programs. The System Development Program works with the clinical programs to improve the provision of enabling services to all children with special needs in the areas of transition, cultural sensitivity and improved access to SSI services. Case management and other enabling services are provided to children who are followed in clinics or early intervention centers and to children served by dedicated case management programs such as the Fostering Healthy Children Program and the Technology Dependent Waiver.

Clinic and care coordination services provided by CSHCN programs include Hearing, Speech and Vision Services; Early Intervention; Child Development Clinic; Neonatal Follow-up Program; Adaptive Behavior and Learning Environment Clinic; Fostering Healthy Children; and the Technology Dependent Waiver Program. These direct and enabling services are described in more detail in the Overview section. The CSHCN Bureau itinerant clinics hold community coordination meetings with local medical home providers, public health or mental health workers, human service workers and families as well as family advocates to develop a multi-agency care plan for each child evaluated in the multi-disciplinary CSHCN clinics.

CSHCN complements private sector services by continuing direct or enabling community-based services if there are gaps in these types of services for children. A combination of State CSHCN programs, rural or local health department clinics, private providers and medical homes provide services for Utah's children and youth with special health care needs. The CSHCN Bureau has been working with pediatric offices throughout Utah to enhance their capacity to provide medical homes for children with special needs and their families. Division staff members provide technical assistance, consultation (administrative and clinical), training and/or mentoring as needed to local health departments, contracted private providers, medical homes and community health centers that provide services to mothers and children.

Through the Utah Collaborative Medical Home Project, CSHCN, in collaboration with the University of Utah, is implementing a statewide system to support primary care physicians in providing medical homes for children with special health care needs. As part of this system, a website was developed to meet the needs of the practices to provide coordinated, comprehensive and family centered care. The MedHome Portal www.medhomeportal.org provides users with up-to-date information on chronic diagnosis, practice guidelines, care coordination, and statewide resources. The site also includes a module directed at families, a transition module with resources, and an education module directed at physicians, care coordinators and families. The website is a work in progress as the site is continually updated with information and new modules. Information is primarily directed toward primary care physicians however it is readily accessible to families of children and youth with special health care needs and other health care or educational providers.

Through a state/local partnership in nine rural areas, the CSHCN Bureau contracts with local health departments to provide on-site nursing case management and clerical support services, including scheduling of clinics, providing follow-up after specialty clinics are held, management of records and development and implementation of individual care plans. (See Community Based Services map.) The Bureau also contracts with the private non-profit parent organization Liaisons

for Individuals Needing Coordinated Services (LINCS) for parent consultants to attend clinics, provide family advocacy and assist in the promotion of family-centered care for children seen in the itinerant clinics. The nurse case manager is responsible to assist the patients' medical home and families by coordinating specialty and tertiary care. The Bureau of Children with Special Health Care Needs contracts with four local health districts to coordinate clinical services for the itinerant clinics in the rural areas of the state. State staff meets with local health officers and nursing directors on an as needed or requested basis.

CSHCN included the Navajo Reservation-based Montezuma Creek Community Health Center in the initial 2001 Utah Medical Home Project. This practice site team, one of five teams to participate in the Project, included the family practice provider and an identified team of a nurse and family advocate throughout the three-year Medical Home Training Project. Although the grant has ended, this practice team continues to be an active medical home site as they have added four members to their team, including a physician assistant, a medical assistant and an administrator. One of the other sites initially involved in the Medical Home Program was the Northwest Community Health Center, a community health center clinic in Salt Lake City serving a primarily Hispanic population.

CSHCN supports a full-time Coordinator and a part time Family Advocate for the Medical Home Project and now serves nine primary care medical home practices around the state through technical support, monthly phone conferences, email broadcast resource information, office trainings and family advocate support. A quarterly medical home newsletter, which is sent out to all pediatricians and family practitioners in the state, is topic oriented and includes local, state, and national resources pertaining to each topic. The Project has an advisory committee with representatives from the community including families, educators, mental health providers, clergy, ethnic groups, physician specialists, and school nurses.

Since SFY01, the Utah Department of Health has received an annual appropriation of $4 million for tobacco control programs from the Tobacco Master Settlement Agreement. Additionally, in SFY03, the UDOH received a $3 million allocation of tobacco excise tax revenue resulting from a cigarette tax increase. Services offered through the Tobacco Prevention and Control Program (TPCP) are available statewide, through a variety of mechanisms, including local health department contracts with staff designated to coordinate local services. Since 80% of adult tobacco users become addicted to tobacco in their teens, local and statewide tobacco use prevention efforts focus on youth. Mini-grants to community organizations, particularly those who serve population groups at higher risk for tobacco use, are disseminated based on their potential to promote positive health practices that aim at preventing underage tobacco use and providing information and programs that enable target audiences to quit tobacco use.

A primary goal of the Tobacco Prevention and Control Program (TPCP) is to provide leadership and guidance to build capacity for comprehensive, science-based tobacco prevention and cessation programs at the community level. By means of collecting and summarizing tobacco-related data, the TPCP identifies the extent of youth-specific, tobacco-related issues and problems. This information is used by state/local health departments and other partnering agencies to develop and carry out targeted interventions. The TPCP is comprised of program specialists who primarily focus on: prevention; youth access; teen and adult tobacco quitting programs; secondhand smoke/Utah Indoor Clean Air Act; counter-marketing; tobacco control policy; partnerships with health care providers; and surveillance and evaluation. Besides acquiring or developing specific program materials, specialists promote adoption of strategies, programs, and activities to the public and to collaborating agencies.

Partnering agencies promote changes in tobacco-related policies and provide services and activities to prevent Utah's youth from becoming dependent/addicted to tobacco. The Tobacco Prevention and Control Program's collaborates with many partners including: local health departments; State Office of Education and local school districts; the Utah Tobacco Quit Line and Utah QuitNet; the Utah Juvenile Court System; American Cancer Society, American Heart Association, and American Lung Association, Utah Medical Association, Utah Dental Hygienists Association, Utah Dental Assistants Association; Chiefs of Police Association and Utah Sheriff's Association; Utah Substance Abuse and Anti-Violence Coordinating Council; the Utah Department of Human Services Division of Substance Abuse and Mental Health; the Coalition for a Tobacco Free Utah; and many others. While it takes extra time and effort to activate collaborations with "sister" agencies, the payoff in terms of results, quality, and effectiveness of youth-related tobacco programs is great.

A multidisciplinary advisory committee with representation from community agencies, educational institutions, and other state agencies advises the TPCP on how to use the funds. The Tobacco Prevention and Control Program allocates funds through a competitive process in the following areas: media and marketing; local interventions focused on comprehensive tobacco prevention education, policy change, and referral to quit services; projects focused on reducing tobacco-related disparities; telephone and web-based quit services; partnerships with health care providers; and evaluation of efforts.

The Tobacco Prevention and Control Program (TPCP) works with Medicaid in the coordination of media campaign efforts. Utah Medicaid provides tobacco cessation benefits for pregnant and postpartum women through cessation programs and appropriate medicinal therapies to facilitate cession. The TPCP collaborates with school districts to implement the CDC's Guidelines for Comprehensive School Tobacco Policies; the Phoenix Alliance, Utah's youth movement against tobacco, trains youth advocates across the state in street marketing techniques; local health departments provide community-based prevention education, engage youth in efforts to increase the number of tobacco-free recreational sites, and collaborate with courts to provide tobacco cessation programs ("Ending Nicotine Dependence") to youth who violate Utah tobacco possession laws. In addition, the TPCP works with local health departments to develop and offer telephone or group-based tobacco cessation programs ("First Steps") for pregnant women. Further efforts to provide comprehensive quit services to pregnant women include partnerships with Medicaid, Utah's Primary Care Network (PCN) and the Utah Association of Community Health Centers (AUCH).

Impact of "Emerging Issues" on State's Ability to Provide Direct and Enabling Services

One emerging issue that is of concern in Utah, as in other states across the country, is the increasing premiums that obstetric providers are required to pay for malpractice insurance. Increased medical malpractice insurance rates for Utah physicians and mid-level providers may be discouraging students from specializing in obstetrics as well as forcing some family practice physicians from continuing to provide these services. The Utah Chapter of the American College of Obstetricians and Gynecologists recently implemented a survey among its members to try to determine the extent of the issue here in Utah. Survey results indicate that among respondents (108), over 28% are no longer currently providing obstetrical services and the primary reason why they stopped providing obstetrical services was professional liability concerns. The following comment from a recent PRAMS survey respondent validates this fear; "I had to switch doctors

because my regular OB couldn't see me because of mounting malpractice insurance". Provider shortages could be affecting Utah women's ability to gain early access to prenatal care. Among PRAMS respondents who did not receive prenatal care during the first trimester and indicated that they wanted to receive care earlier, almost 22% cited "could not get an appointment as the reason".

Utah has also experienced an influx of Spanish-speaking immigrants many of whom are of undocumented status. From 1999 to 2003, the number of live births to Hispanic women rose from 5,455 (11.8% of live births) to 7,086 (14.2% of live births). According to the Utah Health Status Survey of 2001, the last year for which data are available, 25.8% of Hispanics had no health insurance compared to 7.2% of non-Hispanic residents who were uninsured. The 2005 Legislature passed a law that no longer allows anyone of undocumented citizenship status to be issued a driver's license; rather, they are issued a driving permit, which cannot be used by any government entity in the state as a form of identification. This restriction may serve as a barrier for undocumented workers in obtaining services regardless of the funding source, i.e., WIC.

The low rate of children's access to dental care, especially those on Medicaid, has been very concerning. Utah has the lowest Medicaid dental reimbursement rate in the nation, making it difficult to engage dentists to see Medicaid children for care. It is anticipated that problems of access to routine preventive dental care for children, youth and adults with special health care needs will persist over the next five years. Some of the barriers include: many dentists are reluctant and/or not trained to treat children and youth with disabilities in the traditional office setting; and, many children and youth with disabilities are Medicaid participants.

The new federal language under the Child Abuse Prevention Treatment Act (CAPTA) requires that all preschool children with substantiated cases of abuse and neglect be referred to the Early Intervention Programs for screening and treatment. This federal requirement could potentially have a great impact on the volume of referrals and number of children who are served by the Baby Watch/Early Intervention (BWEIP) Program. BWEIP is collaborating with the Department of Human Services, Division of Child and Family Services (DCFS) to develop screening plans as well as policies and procedures for the referrals. The policy will include new DCFS procedures for child protective personnel to utilize a developmental screener for children birth to three at their initial home visit. Children who show potential problems will be referred to the BWEIP. Local BWEIP service agencies will partner with local DCFS personnel to train on the developmental screener and to design procedures for referral of children suspected of having a developmental delay. BWEI and DCFS have received a $10,000 grant from the National Association of State Directors of Special Education to support this work.

Another potentially large issue is the possibility of de-funding the Early Hearing Detection and Intervention grants nationwide and asking state Title V to fund the programs. On-going discussions at combined Federal CDC and HRSA Early Hearing Detection and Intervention (EHDI) meetings have suggested the possibility that HRSA EHDI funds could be rolled into the Title V Block Grant, effectively reducing the state Title V funding. Blending funds previously earmarked for specific programs (in this case the identification of newborns with hearing loss) into the general Block Grant funds could create additional financial obstacles, especially in the states where the required hearing-screening outcome has been legislatively mandated. Additionally, this change could impact other CSHCN programs that would lose funding if they are required to shift funding to the hearing screening efforts.

If the federal preventive block grant is defunded, the state will need to review the services provided by the grant, which may result in reallocation of some of the state's Title V dollars.

Children's mental health access, quality and funding have been a persistent issue in Utah and the nation over the past 10 years. In 2004, the Department of Human Services, Division of Substance Abuse and Mental Health received a grant to collaborate in improving the Mental Health Service System infrastructure throughout Utah called "Utah's Transformation of Child and Adolescent Network" (UT CAN). The five-year $750,000 per year grant will be a collaborative initiative, involving multiple agencies, including the state Title V Director, and the Directors from both the MCH and CSHCN Bureaus, along with key Division and Department staff.

Local health departments have moved away from direct services to providing more services that are enabling or population-based. FY06 MCH contracts for the local health departments include a requirement for a local needs assessment of the community, as well as assessment of capacity in the community and within the local health department. The needs assessment, which was modeled after the NACCHO (National Association of County and City Health Officials, 2002) document, "Making Strategic Decisions about Service Delivery: An Action Tool for Assessment and Transitioning". The purpose of the needs assessment is to encourage local health departments to look at community needs and capacity to ensure that the services offered address the identified needs effectively.

Availability of prevention and primary care services

Direct and enabling health care services in Utah are available through both public and private providers. Local health departments and community health centers are critical resources for services for the maternal and child health populations. In Utah, local health departments and 10 community health centers, as well as the migrant centers provide public care. Recently two new free health centers were opened in Salt Lake County to attempt to address the demand for health care services for low-income uninsured individuals. Local health departments provide direct and enabling services, but no primary care. Services for children with special health care needs are provided by the State CSHCN programs, rural clinic sites in collaboration with local health departments, and through private providers.

Division staff provides technical assistance, consultation (administrative and clinical), training and/or mentoring as needed to local health departments and community health centers providing services to women and children, such as prenatal, family planning, immunizations, and nurse home visiting and school nursing. Program monitoring and data collection are conducted at the state level to assist in program planning and evaluation.

Each local health department determines which MCH services it will provide based on available resources, community priorities and need. The Division provides each district with MCH block grant funds for provision of services for the MCH population, although each varies in offered services. Clearly, demand and need for services exceed the system's capacity to provide them. The requirements of the MCH Block Grant contracts have been changed to focus on core public health functions. The contracts require a local needs assessment, capacity assessment, and identification of priority needs in the district along with development of a plan to address the identified priorities.

Reproductive health services, of varying degrees, are available in all twelve local health departments. Direct prenatal services are available in two Wasatch Front local health departments, Salt Lake Valley and Weber-Morgan Health Departments, through a contract with the University of Utah Health Sciences Center, to utilize these agencies' facilities and support staff in providing low-cost prenatal care. Presumptive eligibility screening and various enhanced prenatal services are available at both sites. Both programs serve numerous Hispanic women, many of who are of

undocumented citizenship. Although both clinics employ bilingual personnel, many providers must utilize interpreters to communicate with women served in these clinics.

Ten local health departments provide perinatal care coordination (PCC). Perinatal care coordinators assess prenatal clients for risk factors that might negatively affect their pregnancies, develop action plans based on these risk factors, and assist clients in obtaining needed services throughout their pregnancy and postpartum periods. The actual number of perinatal care coordination visits varies across local health districts and even between the various satellite sites within a health district. Nine of the local health departments that do PCC also provide pre- and postnatal home visiting for Medicaid women. Again, the extent of home visiting varies across local health districts and between a health district's offices. Some health districts visit many of their prenatal mothers; others visit only those at extremely high risk and some lack staff to provide prenatal home visiting services at all. One local health department provides presumptive eligibility only.

Local health departments in Utah are required to report the number of unduplicated individuals they provide services to along with race/ethnicity and insurance status annually. Usually the clinic visit is for presumptive eligibility screening not direct care. Insurance status for women seen for family planning services during 2004 indicated that of the women for whom health coverage was reported (only 57% of women seen had health coverage reported by the LHD) 51.3% had no insurance coverage, 4.7% had private insurance and 1.0% had Medicaid. Health coverage status for women seen for prenatal care during 2004 indicated that of the women for whom this was reported (88%) 48.0% had Medicaid, and 35.5% had no insurance coverage, and 3.9% had private insurance.

Most family planning services in the state are provided through private providers, community health centers and Planned Parenthood clinics. However, family planning services are available at 8 of the local health departments via midlevel providers. Three health districts provide indirect family planning services by subsidizing clinical evaluation by local private providers and /or by providing discounted Depo-Provera and oral contraceptives to qualifying women. These local health departments also provide education regarding various contraceptive methods, obtain health histories and refer to local providers. One rural local health department provides no family planning services and no community health center or Planned Parenthood clinic is available within the district's boundaries.

Given that the vast majority of women (89.8%) seen in local health departments for family planning services report no insurance and only 1.8% report being on Medicaid, funding for family planning services for low-income women in Utah is problematic. Many women lose their Medicaid coverage two months following delivery and are then without financial means to obtain effective contraception. While the Primary Care Network (PCN) does cover family planning services, it has limited enrollment periods, requires an enrollment fee many women cannot afford and is limited to U.S. citizens. MCH Block Grant funds to local health departments can be utilized for family planning services. However, these funds are inadequate to cover the increased costs of family planning services. Almost all local health departments must limit the types of contraception that can be offered due to budget limitations. Thus, the newer contraceptive measures and IUDs are infrequently available through the local health departments. Additionally, the MCH Block Grant requirement to provide services at no cost to women with incomes under 133% of the Federal Poverty Level results in a heavy financial burden to the local health districts. At least one local health department has had to place a cap on the number of women it can serve. The inability of some local health districts to purchase discounted Depo-Provera and oral contraceptives has led

them to form informal purchasing collaborative. However, if more local health districts are unable to obtain discounted contraceptives, continuation of family planning services in some districts, especially in rural areas of the state, is in doubt. One local health district is no longer able to purchase Depo-Provera and has had to remove this contraceptive option from their formulary. Due to state legislation requiring written parental consent prior to providing family planning information or services to an unmarried minor, the local health departments are required to obtain parental consent for minors seeking services. Title X funds are awarded to Planned Parenthood Association of Utah (PPAU); however, PPAU is not able to cover all the needs in the state, especially in the rural areas where there may be no Title X clinic or provider. The State does not allocate any state funds for family planning services, thus limiting the services even more.

There are currently VFC providers in 300 sites throughout the stat e for VFC eligible children to obtain immunizations. There are currently 71 public VFC provider sites and 229 private VFC provider sites. However, some areas of the state may have low numbers of VFC providers, which may pose a barrier to eligible children accessing needed immunizations. The Immunization Program has been working to expand its VFC provider network to most Medicaid providers, as well as with other providers in the state. All local health departments, community health centers and migrant health centers are VFC providers, making low cost immunizations available in most communities.

Individual nutritional counseling for women at high nutritional risk is available through WIC or private registered dietitians. Psychosocial counseling is also available, usually by county mental health programs to the same group of women. Medicaid reimbursable group childbirth education is offered through most hospitals.

The Utah WIC Program has 54 clinic sites throughout the state serving approximately 74,000 women, infants and children. Clinics are located in urban and rural areas, including a Ute Indian reservation clinic, homeless shelter clinic and the University of Utah Teen Mother and Child Program. Rural areas often staff several satellite clinics offered throughout the month. Because multiple counties are incorporated into rural health departments, clinic hours are more limited than those in urban sites, which are generally open more days in offer a larger range of clinic hours to meet participant needs. Rural clinics tend to have more personalized and efficient services, while urban clinics are staffed with a greater number of Registered Dietitians and bilingual staff.

Local WIC staff analyze the CDC Pediatric (PedNSS) and Pregnancy (PNSS) Surveillance data annually to identify specific areas of declining nutrition and health-related indicators, such as increasing rates of anemia, obesity an / or malnutrition as reflected in inadequate weight gain or growth patterns. Following the analysis, local WIC staff develops goals and action plans to reduce the prevalence of these increasing rates of adverse health indicators.

In the Utah WIC Program, two new effective nutrition intervention strategies, Family Centered Education and Facilitated Group Discussion, have been implemented to increase family involvement and interaction. These strategies have resulted in positive behavior change related to improved nutritional consumption and greater physical activity among WIC participants.

In 2004, the Utah WIC Program received $148,000 from the USDA to implement the *Best Start Loving Support* Breastfeeding Peer Counselor Program. The funding will enhance the infrastructure of the Peer Counselor Program by increasing the work hours of existing per counselors, hiring new peer counselors, raising the hourly salary rate, and providing training for all peer counselors to maintain a current knowledge base. Enhancing the Peer Counselor infrastructure and increasing the training will provide better support for breastfeeding mothers. It is known that utilizing Peer Counselors within the scope of the overall services provided to WIC participants will

result in an increase in breastfeeding initiation and duration rates. A major benefit that Peer Counselors provide to breastfeeding mothers is the peer mom-to-mom support with anticipatory guidance for the prevention of problems, such as sore nipples, improper positioning, and engorgement, as well as early appropriate referrals for medically related problems, such as thrush, mastitis, etc.

At present, the WIC Program has sufficient funds to serve the existing level of participation however, if the current caseload continues to increase, some participants may have to be removed from the Program. Rising food costs, level funding and increased participation in WIC have raised concerns about the potential need for caseload management in the Utah WIC Program for FY2005 and/or FY2006. Utah's increasing birth numbers may create difficulty in serving all eligible women and children.

All but one local WIC clinics are housed in local health departments, which help facilitate referrals and coordination of many needed services. WIC serves as a referral source to many preventive and primary care programs. Since local WIC staff sees participants at regular intervals over an extended period, they are a vital link in providing access to other services. Women who have not received prenatal care at the time of enrollment into WIC are assigned the risk factor "Inadequate Prenatal Care", referred to prenatal care, and tracked until care has been established. WIC staff also refers participants to Medicaid and CHIP if not already enrolled. Some WIC clinics coordinate with other services such as well child exams, immunizations, Baby Your Baby appointments, and family planning.

The Division of Community and Family Health Services and the State WIC Program work with the WIC Advisory Council, which includes representation of local WIC clinic administration, local vendors, advocacy groups as well as WIC participants. The focus of the Council's input has been broadened from budget issues to include program issues, such as access to services, certified versus vouchered participants, and policy changes, e.g., three-month vouchering. The Council has provided important input into program issues that have arisen.

Utah CHIP began enrollment in August 1998. The program provides coverage for dental services through Public Employees Health Program (PEHP). The program has been successful in providing access to needed dental care for CHIP-enrolled children. Although Utah CHIP has proven a valuable resource to enrolled children, the scope of CHIP dental benefits is not as broad as that for children enrolled in CHEC/EPSDT.

Substantial numbers of low-income children still remain without dental insurance, and do not qualify for CHIP because they have some medical insurance. An estimated 13,000 to 19,000 of Utah children between 100-200% of the Federal Poverty Level have health insurance, which does not include dental coverage. In order to address this concern, CFHS is currently working with the Regence Blue Cross/Blue Shield (BC/BS) Caring Foundation, which has established a program for these children to receive services from a BC/BS dentist. The scope of services provided through the Caring Foundation is identical to those provided by PEHP dentists to children enrolled in CHIP and is available statewide. In 2004, the Caring Foundation was able to provide dental services to over 1000, uninsured children in Utah.

In Utah, the BabyWatch Early Intervention Program (BWEIP) is a significant provider of therapy services, especially in rural areas. BWEIP serves over 5,000 children per year and anticipates a growth rate of 10% per year because of identification of eligible children, eligibility changes to include very low birth weight (<1000 grams), the program's excellent reputation, and increased collaboration with physicians.

Provider shortages and underserved geographic areas

Provider shortages exist throughout the state, except along the Wasatch Front. The maps at the end of this document detail areas of the state with provider shortages for medical, dental and mental health providers. An additional map details the medically underserved areas of the state.

Access to reproductive health care varies depending on the geographic area of the state. According to Health Professional Shortage Area surveys conducted between 2000 and 2004, there are areas in Utah with high ratios of women of childbearing age to providers, resulting in limited access to a prenatal provider in their area**.** Women in rural communities may have to travel many miles to a provider and/or hospital. More than half of the counties (16 out of 29) are without any obstetrician-gynecologist with several counties reporting as few as 1 provider to 10,000 women of childbearing age. There is a need to promote collaboration to assure better access to consultation services for rural providers.

Rising liability insurance premiums has risen to the level of high concern among obstetrical providers in the state. Some providers have indicated that they are leaving or contemplating leaving obstetrical practice due to unmanageable overhead costs for relatively stable reimbursement rates. Utah's Governor Huntsman has said, "In 2002, there were no University of Utah medical school graduates in obstetrics. In 1972, there were 84 applicants for only four slots in obstetrics. You've got a rate-limiting issue for doctors. They're paying $75,000-80,000 in insurance to ward off frivolous litigation. … If a doc goes to court, the average cost is $325,000." (Salt Lake Tribune)

Local agency staff to assist with presumptive eligibility determinations for prenatal Medicaid has been problematic in some areas of the state, especially in the urban areas with limited Presumptive Eligibility (PE) sites, mainly due to lack of reimbursement for this service. The Division has instituted the "Baby-Your-Baby by Phone" project to cover this unmet need. This project provides PE screening over the telephone for Salt Lake County women and screened close to 2000 women for PE last year. Co-location of PE workers and Medicaid eligibility workers has assisted women in accessing Medicaid eligibility faster. For those sites where the waiting times for appointments are too long, clients are referred directly to the Department of Workforce Services' workers to make a direct Medicaid application.

Fifteen counties in Utah lacked pediatricians and one overlapping county lacked a family physician. Access to pediatric subspecialty care is often limited by geography and by the number of subspecialists available. About 220,000 children live in the rural/frontier areas of the state.

Access to dentists in Utah is a major issue, particularly for Medicaid participants and for individuals living in rural or frontier areas of the state. The Oral Health Program initiated an Oral Health Summit designed to look at issues related to oral health in the state with the plan to develop workgroups to identify priorities and strategies to address these issues. The difficulty of finding a dentist, especially in the rural communities, was identified as a major barrier to oral health care access. One solution suggested was the inclusion of dentists and possibly dental hygienists in the state primary care grants and in the loan repayment program for working in health professional shortage areas. The legislature has created the Utah Health Care Work Force Financial Assistance Program and now dentists are eligible for loan repayment opportunities for working in rural dental health professional shortage areas.

Shortages of public health nurses is becoming more apparent as the workforce ages and new nurses coming into public health often have little if any formal public health training or experience. In a 2004 survey of public health nurses in the state, almost 60% of respondents indicated that they had worked in nursing16 or more years. Although 36% of the nurses had bachelor's degrees, 43% had an associate degree in nursing. More than half of all respondents indicated that they had had

less than half a semester to a semester of public health nursing or principles of public health. About 60% of respondents indicated that they had had less than a half semester or semester of clinical public health experience during their education. Almost 50% (45%) indicated that they had learned public health on the job, with 27% indicating they had no formal training on the job.

Nursing shortages in general have challenged Utah's health care system, with hospitals offering bonuses to out of state nurses for inpatient care. Scott M. Matheson, gubernatorial candidate in 2004 indicated that "One of the most serious has been the nursing shortage," he said. "We rank No. 3 in the nation as far as seriousness of that problem. We need to look at a nursing initiative proposal in the Legislature. Dixie State College got some support. The bottleneck is on the training side. We just don't have the faculty and training capacity (statewide) to meet the shortage." In partnership with the Utah Department of Workforce Services, the University of Utah College of Nursing received an $871,000 grant in 2005 from the U.S. Labor Department to educate more nursing instructors.

In the past, the Utah WIC Program has had difficulty in recruiting and retaining registered dietitians in the rural clinics and some of the most heavily populated urban clinics. In rural areas, Registered Dietitians cover more than one clinic site due to shortages of registered dietitians and low salaries in public health. In the past some WIC clinic sites have had positions open for long periods. However, at present there are no vacancies for Registered Dietitians in the Utah WIC Program, as a result of broader and more effective recruitment and retention practices.

However, recently, utilizing state and national salary data for registered dietitians, the WIC Director of the largest urban district (Salt Lake) was able to negotiate an increase in salaries for the registered dietitians in the Salt Lake County WIC Program. Two rural WIC Directors for TriCounty and Central Utah were able to negotiate hiring registered dietitians on a contractual basis at a higher hourly rate than that of a full time employee. In addition, a *Nutrition Staffing Resource Manual* was developed by the State Nutrition Coordinator and distributed in November 2004 to all local WIC Directors to assist them in developing strong recruitment and retention action plans to ensure quality staff is available at all local WIC clinics. As it is anticipated that there will always be a challenge in recruiting and retaining registered dietitians, the State WIC Program and local WIC Directors will have to continually evaluate the status to ensure that all provider shortages are addressed in a timely and effective manner. These shortages will need to be addressed by implementing new strategies for hiring and increasing salaries as well as developing strong recruitment and retention plans.

Remote or rural areas of the state suffer from a notable shortage in physical, occupational and speech therapists. The Baby Watch/Early Intervention Program (BWEIP) oversees a statewide credentialing program for professionals in the early intervention field working with children birth to 3 years. BWEIP has agreements with the University of Utah and Utah State University for pre-approved programs of study that will allow graduates in early childhood education to receive the state early intervention credentials.

An example of the shortages of therapists is illustrated by the need for Speech and Language Pathologists (SLP), who continue to be in high demand locally and nationally. A recent Utah State University study reported critical shortages statewide in all related service specialists, such as speech language pathologists, psychologists, physical therapists and occupational therapists. The study indicated that aside from stiff competition in hiring, Utah colleges and universities aren't graduating enough students to meet the demand. Anecdotal information suggests that shortages likely exist in urban and rural areas, school settings, and for the provision of services to culturally and linguistically diverse populations.

CSHCN staff members are also working with Utah Leadership Education in Neurodevelopmental Disabilities (ULEND) trainees to provide direct services for children and consultation to local BWEIP home visiting staff in rural Utah for children under three. Additionally, the BWEIP and the State Office of Education collaborate on the Signal Project, which is a state improvement grant through the Federal Office of Special Education Programs that addresses the recruitment and retention of specialized personnel in early intervention and special education. The grant develops and targets strategies at the pre-service and in-service levels for personnel working in the special education field.

CSHCN works to integrate local rural clinic activities into the statewide medical home effort, and will work closely with local primary care medical home providers to coordinate the care for children. Chart audits will be conducted and follow-up from last year's recommendations will be assessed. CSHCN will work closely with new local health department staff by providing an orientation to the itinerant clinic process. The CSHCN Bureau continues its efforts to improve services to rural children with special health care needs through Telehealth technology. These activities supplement services to rural children with special needs using videoconference technology currently in place through the University of Utah Telehealth Network. The Telehealth Network facilitates long-distance clinical health care, community staffing, patient and professional health-related education and public health.

The UDOH is working to improve application for statewide services for families through a contract with Utah State University in establishing Utah Clicks, a web-based universal application initiative. The program will be operational summer of 2005, enabling families to apply online to five different programs including Medicaid, Baby-Your-Baby, BabyWatch/Early Intervention, CSHCN clinical services and WIC.

Title V staff have actively participated in the Rocky Mountain Public Health Education Consortium (RMPHEC) which provides educational opportunities to increase the knowledge, skills, and capacity of public health professionals, paraprofessionals, organizations and systems in the Rocky Mountain and surrounding states and Tribes within the region. These opportunities are vital for public health workers in the region (and beyond) who otherwise might not be able to access due to the rural/frontier nature of the states in this region. The Consortium has existed since 1997 and is a partnership of academic and public health professionals from state, tribal and county agencies working together to provide workforce development opportunities.

Staff members in the CFHS Division have participated in the MCH Summer Institute, the MCH Certificate Program and in development of some of the Consortium products.

In addition, the Department of Health has collaborated with the Nevada Department of Health to develop the Great Basin Public Health Leadership Institute which offers public health professionals in the two states an opportunity to participate in a year-long educational program focused on public health leadership. The first class of scholars graduated in March 2005, with the second class beginning its work in Mary 2005. The Institute provides scholars with educational experiences that are invaluable in enhancing leadership in public health.

Availability of Specialty Care Services When Needed

The largest percentage of Utah's population resides along the "Wasatch Front", a 100-mile stretch of the central part of the state. This is also the area where all of the tertiary care centers in the state are located, which places specialty care services within geographic reach of the largest percentage of the population. The hospitals located outside of the Wasatch Front, for the most part, consult and refer high-risk patients to specialty and subspecialty care when need arises. Each of the

specialty care centers is equipped with air transport teams to expedite transfer of high- risk patients emergently. However, the increasing rates of very low birth weight births (VLBW) occurring outside of tertiary hospitals equipped for high-risk deliveries and neonates is a concern, with the rate declining from 75.1% in 1999 to 66% in 2003.

Because of continued access problems to multi-disciplinary evaluation clinics and early intervention services for children and youth with special health care needs, the Bureau of Children with Special Health Care Needs continues to provide direct and enabling services to children in rural/frontier and urban/suburban Utah. These core clinical programs include: Neonatal Follow-up Program, the Child Development Clinic, the Adaptive Behavior and Learning Environment Program, and the School Age and Specialty Services Program. The School Age and Specialty Services Program also addresses access to specialty services for children with special health care needs, which is an especially difficult problem in rural Utah. Through collaborative and contractual agreements, children are seen at Primary Children's Medical Center for neurology, cardiology, genetics, orthopedics, spina bifida, and oral facial clinics. Children also receive collaborative specialty services through Shriners Hospital for Children for orthopedic conditions, including osteogenesis imperfecta.

The Bureau of CSHCN contracts with five local health departments to continue itinerant clinics in nine rural sites across the state, including: St. George, Cedar City, Ogden, Provo, Price, Blanding, Moab, Vernal and Logan. Due to state-level budget cuts in 2004, responsibilities for the contracts and itinerant clinics were transferred to the two CSHCN Bureau clinical programs that staff the clinics: the Child Development Clinic (CDC) and the System Development Program (SASS). Through the contracts, registered nurse care coordinators and clerical staff at the local sites schedule clinics, complete encounter forms, send out appointment letters, call families, provide care coordination services, arrange tests, collect reports and maintain patient charts. CSHCN provides ongoing consultation and support on care coordination issues to contract staff. CSHCN supports an Access software database used by each site to schedule clinics and collect patient data. Information on resources and clinical processes has been provided.

Cultural acceptability

The 2000 Census revealed that the largest proportion of ethnic minorities in Utah to be of Hispanic or Latino origin (9.0%), followed by Asian (1.7%), Native American (1.3%) and other minorities (<1%). Since 2000, there has been a 14.3% increase in the Hispanic population (from 204,254 to 233,425). By 2003, Hispanics accounted 10% of state's total population. Currently, one out of every ten Utahns belongs to an ethnic or racial minority group and these populations are growing more than twice as fast as the state population as a whole. The challenges become even greater in establishing and maintaining family-professional partnerships when the family is not from the predominate culture. The summary from the Utah Health Status Survey on Ethnic Populations (Utah Health Status Survey on Ethnic Populations-Qualitative Component, Bureau of Surveillance and Analysis. 1997. Utah Department of Health) found that members of culturally diverse families (Asian-American, Latino, American Indian, African American, and Pacific Islander) indicated barriers in forming respectful partnerships with health care professionals and generally expressed the view that their own beliefs were not honored and that-providers just focused on practicing "Western Medicine". The Department released the 2004 Health Status Survey data on race and ethnicity in a report released in May 2005. The report is available on the following website: ibis.health.utah.gov/ophapubs.html. The report includes race and ethnicity data on maternal and child populations in Utah as well as other health issues, such as infectious disease,

cancer, injury, etc.

Utah's predominantly white, non-Hispanic population distribution creates difficulties for our racial and ethnic minority populations as health care providers often lack knowledge and sensitivity to their cultural differences and beliefs about health care and needs. For example, in the Tongan language, there is no work for "prevention", making it difficult to convey the value of prevention versus treatment. Advocates for racial and ethnic minorities promoted and passed legislation in 2004, which provided state funding for a Center for Multicultural Health, which is housed within the Utah Department of Health's Division of Community and Family Health Services. The 2005 Legislature appropriated additional ongoing funding for the Center. This Center is currently developing strategies to address needs and improve health care for our racial and ethnic minority populations. Additionally, the Department's Ethnic Health Advisory Committee provides input to programs on concerns of communities that are beneficial in program planning efforts. The Chair of the Advisory Committee participates in numerous other efforts of the Department and is a great advocate for the minority populations in the state. The Department of Health also filled the vacant Native American Liaison position, which is housed in Medicaid. The Liaison has established relationships with program staff in the Division of Community and Family Health Services and is working with staff to identify strategies to improve the health care status and need of the Native American population in Utah. The Department of Health strives to make data available on health status of ethnic and minority populations as much as possible. Small numbers often pose a barrier to publishing the data due to concerns regarding its reliability. Department Center for Health Data staff is working with the Director of the Center for Multicultural Health and the Native American Liaison to develop an updated report on the health status of ethnic and minority populations.

Utah has a unique population whose health care needs are challenging to address, the families living in polygamous communities around the state. During the past two years, the Child Adolescent and School Health staff has been working with representatives from the communities to provide diversity training on the culture of polygamy to public health nurses and other public health professionals at the state public health conference. Additionally, the staff has worked with the Attorney General's Office, other state agencies, and community advocacy groups to develop materials for state agency workers on the complexities of the polygamous population and resource referral information.

Programs providing services to the Hispanic population are increasingly developing resources for Spanish-speaking families so that they have the same access to information that English-speaking families do. Programs have expanded websites to include pages for Spanish-speaking individuals. Print materials and other resources have been developed in Spanish. While we recognize that cultural differences extend beyond language, programs are continuing to evaluate methods in which they can outreach to disadvantaged populations, including those of ethnic or racial minority. With the Department's Center for Multicultural Health and the Native American Liaison staff members in place, programs are anxious to work with them to improve their cultural sensitivity and appropriateness. They will meet with MCH Bureau staff during the summer to increase awareness of issues faced by ethnic and minority populations in the state. The Reproductive Health Program has developed its website in English and Spanish. Other programs have also developed Spanish-language materials.

Utah data from the National CYSHCN Survey note significant disparities between Hispanic families and white families in several categories. When asked whether Utah CYSHCN usually or always have family-centered care, 73.3% of the white families responded positively compared to

only 57.4% of Hispanic families. In Utah, the usual source of health care also showed discrepancies with 10 % fewer Hispanics families receiving health care at a doctor's office than among white families (61% Hispanic to 71% white). These demographics simply underscore the increasing need for education and resources to provide optimum health care for children and youth with special health care needs from minority populations.

CSHCN continues to improve its cultural acceptability to children and families from varied cultural backgrounds, though much work needs to be done. The Bureau provides cultural awareness training for staff and contract providers, in addition to providing written training and resource materials. Bureau staff has met with the Ethnic Health Advisory Board and the DOH Native American liaison to open dialogue about improving outreach and services to children and youth with special health care needs and families from the different Utah cultural populations. The Bureau's largest minority population served is children from Spanish-speaking families. CSHCN has made an effort to hire Spanish-speaking staff, to translate training materials and application forms into Spanish and to have Spanish signage in clinic areas. Two of the nine medical home teams established with the Bureau's support over the past five years serve predominantly low income and Spanish-speaking families and children. One of the nine teams provides care through a family practice community health center located near the Piute Indian tribes. CSHCN clinics along the Wasatch Front have access to interpreters and translation services through state contract, and the AT&T language line is available in all clinics.

The MedHome Portal website staff is discussing ways to improve the information for providers on being a culturally effective medical home provider. Some forms, such as care plans and emergency medical information forms available on the MedHome portal, have been translated into Spanish, and it is anticipated that more information will be translated in the next year. The CSHCN Medical Home program manger and the CSHCN/Utah Family Voices director are on the advisory committee to the University of Utah, Department of Pediatrics Community Access to Child Health (CATCH) grant, which targets Latino families with children and youth with special health care needs to determine the need of this population and the barriers to accessing services.

More local health departments and community health centers have worked to hire bilingual health professionals to better meet the needs of the increasing non-English speaking population. Since the major ethnic group in Utah is Hispanic, clinics have attempted to address the needs of the Hispanic population by hiring bilingual staff. However, other groups in the state are growing in numbers that are also hard to reach due to language barriers, cultural barriers, and provider acceptability.

Linkages to Promote Provision of Services and Referrals between Levels of Care

In Utah, there are five tertiary centers for perinatal health care and two tertiary centers for children's health care. Each center has University of Utah College of Medicine faculty assigned and is well recognized throughout the state and the Intermountain West as premier consultation and referral centers for obstetrical and/or pediatric cases. These centers work with hospitals within their referral areas to encourage consultation and referral as needed, depending on the condition of the mother, infant or child.

The Reproductive Health Program has worked to implement a variety of strategies in an attempt to reverse the trend of increased percentages of very low birth weight infants delivered outside Level III perinatal centers. Changing hospital services, including several Level II hospitals hiring neonatologists to care for VLBW infants born in their facility without the benefit of a maternal fetal medicine specialist to ensure that the mother's care is optimal for her and her baby

prior to delivery, have played a role in this trend. Medical records case review work has indicated that infants in the upper weight ranges (1,000 to 1,500 grams) of the VLBW category are receiving acceptable neonatal care equivalent to a level III standard in several level II nurseries in the state where the majority of these VLBW births are occurring. In order to promote compliance with the ACOG/AAP *Guidelines for Perinatal Care,* the Reproductive Health Program worked with the Department's Bureau of Licensing to rewrite the Utah Administrative code related to hospital perinatal services. The code changes included specific details regarding the standard of care required for labor and delivery services, which had previously not been included in the code.

Intermountain Health Care (IHC), the largest integrated health care system in Utah, owns almost half of the delivery hospitals in the state with a network of over 3,000 health care providers. As a result of the Utah Code amendment of rule 432-100-17, the Director of IHC's Women and Infant Services has been collaborating with the UDOH MCH Bureau Director and the Reproductive Health Program Manager for input into revising IHC's Perinatal Program Standards for obstetric and neonatal hospital care to better reflect the new rule requirements. Although these revised standards will still most likely result in some VLBW babies being delivered at level IIB hospitals (there are three in the IHC system), the standards should go a long way toward improving the hospital standards for the VLBW infants born in IHC facilities. Continued collaboration to assess the impact of these revised standards will be ongoing.

Because the other half of the delivery hospitals throughout the state are owned by other corporations or a government entity, the amended Perinatal Services rule needs to be disseminated to these facilities. Although the rule change should help to clarify expected standards of perinatal care for delivery hospitals throughout the state, market factors exist that may influence hospitals' decisions regarding delivery of VLBW infants in non-tertiary care facilities.

Staff from CFHS interfaces with faculty from these centers through various MCH efforts, including Perinatal Mortality Review, Child Fatality Review, Youth Suicide Prevention Task Force, clinical services, joint projects, and other committee work. Staff participates in a number of efforts led by the faculty, such as the perinatal Epidemiology workgroup, etc. Through these efforts, the need and importance for consultation and referrals between levels of service are emphasized in reports of mortality review findings, or reports on specific topics, such as low birth weight. For example, if through infant death review it is discovered that appropriate consultation and referral were not sought, the coordinator will contact the appropriate referral center to increase their awareness of the need for outreach to community providers and hospitals in their referral area.

The CSHCN Bureau continues to jointly conduct orthopedic clinics with contract University of Utah pediatric orthopedists. Orthopedic clinics are conducted weekly in the Salt Lake area and three or more times per year in the nine rural satellite clinic sites. CSHCN provides physical therapy, occupational therapy, social work and resource specialist support to all the clinics. CSHCN staff provides follow up care coordination for the children and families.

The CSHCN Bureau also continues to contract with local health departments to provide local teams of nurses and health program representatives so that families and local health care providers can coordinate through the teams with tertiary health providers to bring subspecialty care to underserved children and youth with special health care needs in rural areas of Utah. These local teams not only participate in the multi-disciplinary specialty CSHCN clinics and community staffing, but some also help to coordinate Cardiology and Orofacial clinics, which are conducted through agreements between the CSHCN Bureau and the University Of Utah Health Sciences Center.

CSHCN and Shriners Hospital continue to collaborate to help children and families with special needs. Joint osteogenesis clinics are conducted quarterly. Collaboration continues on conducting information fairs for youth with disabilities to provide information and resources on work readiness, transition services and recreation. The CSHCN Transition Specialist works closely with the Shriner's Hospital social work department to coordinate transition services to individual youth with disabilities. The two agencies continue to collaborate on the goals established through the CHOICES (Child Healthcare Options Improved Through Collaborative Efforts and Services) partnership, funded through an MCHB grant based in Kentucky to 1) improve access to care; 2) increase interagency collaboration and coordination; 3) efficient use of public and private resources on behalf of children with special health care needs; and, 4) transition teens to adulthood "healthy and ready to work". CSHCN staff works directly with the Shriners' care coordinators to follow common patients and to make direct referrals to Shriners or from Shriners to CSHCN.

The Ed/Med Task Force is a coalition of state and local public and private health care providers, Medicaid, and special educators who are developing strategies to: 1) improve the coordination of services between health and education regarding expectations, requirements and perspectives; and, 2) to improve the understanding and communication between health and education professionals about children with special health care needs. These strategies will include training opportunities, newsletters and formal agreements between agencies. Additionally, a referral form has been developed and approved by the State Office of Education to facilitate the exchange of information between schools and Medical homes.

Relationship of Title V with Others in the State Who Address Health Care Resources

The state Title V agency works well with the state Primary Care Organization and Association. Through efforts of the State Dental Director, the loan repayment program was expanded to include dentists in an effort to attract dentists to the rural areas of the state.

The Bureau of Children with Special Health Care Needs is a member of the Utah Telehealth Network, a collaboration of telemedicine networks. The University of Utah is a leader in this Network, which strives to provide educational and health access to Utahns, especially in the rural and frontier areas of the state.

Program staff in the Division often serves as mentors or faculty for students desiring public health experience or internships. These opportunities are a good mechanism to promote the work of the State, promote issues for mothers and children in the state, and at times a mechanism to fill vacant positions. Student experiences have by and large been very positive experiences for both the student and state staff. It is not uncommon for students to gain a better sense of future employment goals and content areas.

Many staff is faculty at the University of Utah, Brigham Young University, Salt Lake Community College and other academic settings that allow them to promote their work and dedication to public health. The State Dental Director is frequently invited to present to pre-dental students on the role of the dentist, especially related to the needs of underserved populations.

Population-based Services

Need for Population-Based Services

The award winning Baby Your Baby Program has promoted early prenatal care since 1988. During the initial seven years of the program, the percentage of women starting early prenatal care steadily increased. However, this trend began to reverse in 1995 and recent data indicate that only 78% of women are entering prenatal care during the first trimester. During 2001, Utah's adequacy

of prenatal care as measured by the Kotelchuck Index rank declined to last in the nation in adequacy of prenatal care with only 61.2% of Utah women receiving adequate care. The decreases may be due to several factors including: an increased number of women entering prenatal care after the first trimester, or not at all; women entering prenatal care during the first trimester but subsequently missing visits, and a higher percentage of births with incomplete data for this item on the birth certificate. The Division has dedicated a great deal of effort to determine barriers to prenatal care and ways to address this decline in prenatal care entry and continuity. The Maternal Child Health Bureau Reproductive Health Program conducted research to determine contributing factors to the continued decline in adequacy of prenatal care. Focus group testing of women who received inadequate care helped to elucidate barriers and strategies to improve prenatal care rates. A prenatal care provider survey also provided information on practices that may influence prenatal care rates. We are hopeful that these and other efforts that have been undertaken are beginning to reverse this trend. Data from 2003 indicate that adequacy of prenatal care percentages have begun to increase. The MCH Bureau staff will be working with physicians at the University of Utah Department of Obstetrics and Gynecology to determine how much of the delay in early entry is related to provider practices. Anecdotal reports continue to indicate that women do not get into early prenatal care because providers intentionally delay the first visit. The provider survey that the Reproductive Health Program conducted several years ago indicated that the majority of providers followed the "standard" that pregnant women should be seen early in the first trimester.

Division staff has met with Medicaid staff and provider representatives to discuss low reimbursement issues for prenatal care. These low rates have resulted in fewer prenatal care providers seeing Medicaid participants for prenatal care. With increasing liability insurance premiums and steady or declining rates of reimbursement, providers have joined forces with a union to help negotiate higher reimbursement rates to cover increasing overhead costs.

In October 1987, the Department initiated the Presumptive Eligibility Program to facilitate access to financial assistance for early prenatal care. In April 1990, eligibility for PE was extended from 100% of the federal poverty level to its present level of 133%. During calendar year 2003, 9,215 women were enrolled in the PE Program, representing approximately 65% of Utah Medicaid births that year. Of the women qualifying for the PE Program in 1999, 76.9% qualified for Medicaid benefits compared to only 65% of women in 2003. Women of undocumented citizenship status are referred to either Medicaid outreach workers or the Department of Workforce Services to obtain coverage for delivery expenses through Medicaid's emergency medical program. Despite this, obtaining adequate care for these women is problematic, as emergency services will not cover outpatient prenatal or postpartum care. Women who are without insurance may receive care at a reduced fee through community health centers or the University of Utah Health Sciences Center OB clinics located in 2 Wasatch Front health district facilities or via private providers willing to accept self-pay.

During FY 2000, the Division instituted Baby Your Baby by Phone, which provides PE determination by telephone for Salt Lake County residents. PE applications are completed by phone and the PE card is mailed to the pregnant woman with instructions and referrals to the closest WIC clinic and Medicaid office. The service has been successful in serving almost 2500 women per year. Of the women actually screened for PE in 2004, more than 83% received their PE card. The Program continues to develop strategies to improve successful outreach to women calling in for the service through callbacks and follow up as needed.

To promote early prenatal care, the Baby Your Baby Campaign (BYB) continues to employ various outreach strategies, such as billboards, public service announcements, brochures, and

newsletters. BYB has had high visibility in the state through its ongoing television coverage. The Program continues to provide hotline services which allow the public to call for information about financial and other resources for pregnancy-related and child health care. The BYB staff provide hotline services for numerous maternal and child health areas, such as immunizations, breastfeeding, or questions about specific conditions related to pregnancy or childhood.

As data have become available about women who don't receive early prenatal care, the BYB Program has developed new strategies, such as targeting public service announcements to women less likely to enter prenatal care (i.e., mothers who have had several previous children). It is clear that current public outreach and education must be continued along with messages targeted to hard-to-reach populations, based on specific data that identify barriers to early prenatal care. Ads encouraging planning for pregnancy and financial help for prenatal care are being run in several college newspapers through out the state. The Reproductive Health Program (RHP) has participated in the development and evaluation of the March of Dimes' Teddy Bear Den Project. This project seeks to improve prenatal care of low-income women by offering incentives such as infant car seats and infant supplies to women engaging in healthy behaviors during pregnancy. Division staff has participated in health fairs targeting high-risk populations such as single mothers, uninsured families or those targeting areas of the Wasatch Front with high percentages of racial and ethnic minorities attending.

In an effort to improve adequacy of prenatal care among Hispanic women, KUTV, the local CBS affiliate and one of the partners sponsoring the Baby Your Baby campaign, has contracted for the second year with Univision, the top-rated local Spanish television station in the Salt Lake Valley. Univision carries Spanish Baby Your Baby PSAs airing them during the 5:00 and 10:00 PM news shows and during their highly rated novellas. Baby Your Baby will also have four segments lasting 3 to 4 minutes each on the station's Saturday morning community talk show. These slots will be utilized to promote the importance of prenatal care, the availability of care and healthy behaviors before and during pregnancy. KUTV has also contracted with Busto Media, a major Spanish broadcaster in Utah. Busto stations run Baby Your Baby ads regarding the importance of early and continuous prenatal care. The campaign message of having the first prenatal visit by week 13 and making 13 prenatal visits prior to delivery is also being disseminated through a new Spanish newspaper in the Ogden area. The Baby Your Baby website is also being translated into Spanish.

The Baby Your Baby Advisory Committee, consisting of Utah Department of Health staff assigned responsibility in the area of reproductive and maternal and child health, as well as outside partners, works to promote better access to early prenatal care. During the past 2 years, the Committee has addressed the ongoing concern about Utah's low rank among the states for adequate prenatal care. As a result of combined efforts of PRAMS data analysis, brainstorming, etc. the Advisory Committee developed a new campaign to address this issue by promoting "13-13" (get in before your 13th week and get at least 13 visits) which began early in April 2003. The Advisory Committee is conducting a formal evaluation to determine the impact of the new campaign.

With approximately 50,000 live births per year, over 1,000 infants are born with medically significant birth defects, a major contributor to fetal deaths and neonatal and infant mortality in Utah. Live born infants with birth defects have increased morbidity and for some, mortality. Certain birth defects are more prevalent among different racial groups, higher in Utah than other states or countries and may occur in the first or later pregnancy. In addition, young maternal age is a strong risk factor for some birth defects.

The Pregnancy RiskLine, with its statewide toll-free phone service, was established in 1984 as a joint effort by the Utah Department of Health and the University of Utah Health Sciences Center to address the growing need for accurate information about teratogens in pregnancy and lactation. The Pregnancy RiskLine provides up-to-date, accurate information to consumers and health care providers regarding potential risk to a fetus or an infant due to various exposures whether they are medications, illicit drugs, chemicals, viruses, etc. This information is often not easily accessible to health care practitioners or consumers. Since it is common for pregnant and lactating women to be exposed to medications/drugs, chemicals, infectious agents and other potentially harmful situations, misinformation is common. Although there is an increased sensitivity during pregnancy to the possibility of having a child with a birth defect, women often feel their risk of having an affected child is higher than the actual risk posed by the exposure because of the poor quality of available information. These perceptions of heightened risk have too often led to termination of otherwise wanted pregnancies, increased anxiety, requests for unnecessary and costly prenatal diagnostic procedures as well as repeated screening and testing of the in utero exposed fetus. Since its inception, demand for RiskLine services has steadily increased from just over 2,000 calls in its first year to nearly 10,000 calls in 2004.

The SIDS Program, a component of the Child Adolescent and School Health Program, works with hospitals, childcare providers, and others throughout the state to promote safe sleeping. The SIDS Program develops and distributes pamphlets and offers in-services to ensure they are up-to-date on ways to reduce the risk of SIDS and asphyxiation. With the loss of state funding in 2003, the Department consolidated responsibilities for the SIDS position with those of the child health nurse consultant position. This change provided a single point of contact for local health department for services for families with children.

Although the Utah SIDS rate has decreased substantially along with the national rate, counseling and education about SIDS risk reduction needs to continue, especially those targeted for specific populations, such as low socio-economic status or non-White parents; grandparents and parents who have had children before 1994 who may be less familiar with the strategies known to reduce risk for SIDS; and, daycare providers. Continued public education is critical to reach these groups to further reduce SIDS deaths. As the rates of asphyxiation surpassed SIDS, new SIDS outreach materials and a media article have been developed to emphasize safe sleeping practices to reduce the risk of either cause of death. Sudden Infant Death Syndrome and infant death prevention efforts are addressed with safe sleeping messages through outreach materials to the public and training sessions for child care providers. Although there is no specific funding for SIDS prevention or staff at the state or local levels, Title V funds support these efforts. The Utah SIDS Alliance, a parent support group for parents who have experienced SIDS or infant asphyxiation deaths, and local providers, including faith-based organizations, provide grief support services.

Utah's immunization rates have been one of the lowest in the nation for the past ten years. In 1999, Utah ranked 25th in the nation, up from 44th in 1998, and 51st in 1997. Previously the reported immunization rates in Utah had been for 4:3:1, however, the reporting for the block grant and CDC are now concentrating on the rates for 4:3:1:3:3. In 2000 68.2% of Utah children were immunized for 4:3:1:3:3 which is below the national average of 72.8%. The coverage levels for two year-old children increased from 64% in 1996 to 82% in 1999. The most recent data for 2003 show that for 4:3:1:3:3 Utah children are immunized at 78.8% which is just lower than the national rate of 79.4%. The Utah Immunization Program provides statewide coordination for childhood, adolescent, and adult immunization efforts, as well as other needed technical assistance and support through a variety of mechanisms.

The Utah Immunization Information System (USIIS), a statewide immunization electronic information system. USIIS was developed to simplify immunization record keeping, provide quick access to immunization records and track individual immunization status. USIIS will enable the Immunization Program and health care providers to track immunization rates in an efficient manner. The Registry can serve as a tool to prevent unneeded repeat immunizations due to poor record keeping, and will enable providers to easily track the immunization status of children in their practices.

USIIS has been developed through partnerships with professional organizations, insurance companies, managed care organizations, and public health agencies. USIIS is a central registry to maintain current immunization information for children in Utah, making this information available to authorized public and private providers. Currently, USIIS has enrolled local health department clinics and many private provider offices. As part of data integration efforts, Vital Records exchanges immunization information with USIIS to make immunization records more complete. The Immunization Program is working to enroll school districts in USIIS to help them assess immunization status for school entry rules.

The Oral Health Program has been diligent in establishing and maintaining working relationships with private and public partners. The Utah Oral Health Coalition is the cornerstone of that effort. The coalition provides a forum for sharing ideas and developing projects, which improve the oral health of all Utah residents. The State Dental Plan entitled "Utah's Plan of Acton to Promote Oral Heath: A Public-Private Partnership" is a product of collaborative labors with the Utah Oral Health Coalition. The Coalition will hold a daylong retreat in the fall to discuss future directions and priorities for the Coalition to address over the next 12 months.

Need for State's involvement in direct management of services and programs

Over the past several years, coordination of the BYB media campaign has been shared between the Department and KUTV, with a full-time media coordinator supported jointly by the two agencies. The Reproductive Health Program provides staff support to a multi-agency advisory committee that utilizes perinatal data and expertise to guide the messages developed and disseminated via the campaign. This partnership has proved to be very effective. The MCH Bureau is currently overseeing an evaluation of the media messages that have implemented over the past several years.

The Reproductive Health Program makes information available via its website. Public information on the website includes information about preconception care, family planning, pregnancy, and postpartum. Most of this information is also available in Spanish and is also available in printer friendly formats for those who wish to download it or distribute it. Information is also available to providers and researchers with publications, data, and trainings. The website averages over 5,000 unique visitors per month. The Reproductive Health Program purchases brochures on various subjects as well as producing its own information brochures. These materials are distributed free of charge to local health departments, community health centers, the AIDS training center, various promotora programs, as well as to individuals at health fairs.

The Pregnancy RiskLine provides counseling and appropriate referrals for pregnant women who abuse substances. Staff for this statewide, toll-free telephone resource counsels and educates nearly 10,000 pregnant women, care providers, families and other professionals each year. Approximately 1,000 pregnant women who abuse substances are counseled and referred to prenatal care and drug treatment services each year.

In 1979, a statewide Newborn Screening Program was established to oversee and coordinate newborn heelstick testing of all infants born in the state. Disorders screened include congenital hypothyroidism, galactosemia, hemoglobinopathies, and phenylketonuria (PKU). The cost effectiveness of screening has been well established, with screening for PKU and congenital hypothyroidism saving $3.3 million for every 100,000 infants screened and $93,000 for each identified and treated child. The Utah Department of Health began hemoglobinopathy screening in September 2001. The screening has identified and confirmed two cases of a sickling disease each year (2001-2004). Overall, the rate of abnormal hemoglobin results has been 0.6 % of the screens done. Through this screening, we have identified babies who were transfused but not identified on the demographic cards. The Newborn Screening Program has identified needs including medical translation services and access to a genetic counselor in the rural areas.

The Newborn Child Health Assessment Record Management (NCHARM) has begun to help identify gaps in services. This project, under the Child Health Assessment Record Management (CHARM) and SSDI grant activities, integrates data sets for newborns in Utah by assigning a Birth Record Number on the newborn blood screening form, newborn hearing screening form and the birth certificate. One of the goals was to get all hospitals to assign the Birth Record Number (BRN) to at least 95% of babies born in their hospitals. The Birth Record Number then links records of individual babies in the three databases of NCHARM - vital records, heelstick screening, and hearing screening. This goal was accomplished through in-service training, developing a mechanism for the number to be included with the collection data, and individual targeted education for those hospitals that were below the goal. Monitoring of usage of the BRN was done monthly by comparing the three databases and how many BRNs appeared in each. The Newborn Screening Program form was modified to include peel-away stickers of the BRN. The stickers are applied by the hospital staff to the hearing screening form and the vital records worksheet. Vital records staff and Newborn Heelstick Screening staff have been working together to identify incidences of refusal for screening. Vital records staff has been reminding those providers who stated refused in the BRN in the database to have declination forms signed and a copy sent to the Newborn Heelstick Program. In the future we would like to compare each database to identify missing newborns. Identification of missing newborns in one or more databases will provide information for targeted education about our services and how to successfully incorporate the BRN assignment in hospitals that are having difficulty with compliance. Hearing screening staff and heelstick screening staff have compared their databases for babies who did not have a normal hearing screen. The comparison identified a problem with the BRN assignment in that there have been several babies with unmatching BRNs. Ongoing evaluation of the BRN assignment system will include validation among the three databases to determine if the BRN in each database is identifying the same unique newborn.

The Newborn Screening Advisory Subcommittee has developed criteria for adding or deleting a disorder from the Utah Newborn Screening panel of tests. Using these criteria, the committee has reviewed biotinidase, congenital adrenal hyperplasia (CAH), and Medium-chain Acyl-CoA Dehydrogenase Deficiency (MCADD), and recommended to the Department that they be added to the screening battery. This expanded screening plan will require statewide coordination of efforts to ensure successful implementation and follow through on screens that are positive.

The Utah Birth Defect Network (UBDN) monitors the occurrence of all structural birth defects that occur in known pregnancies in the state. Utah has high rates of particular birth defects: oral facial clefts, gastroschisis and particular congenital heart malformations. The reason for these high prevalence rates is not clear but descriptive analysis is planned for 2005 to assess

epidemiologic characteristics. The Director is currently investigating maternal characteristics and other exposures to determine their risk in the etiology of gastroschisis. The UBDN collects data on the prevalence and distribution of pregnancies and births that are affected by a major birth defect. The UBDN began surveillance activities in 1994 tracking only neural tube defects (NTD). In 1995, oral facial clefts and the common trisomy disorders were included, with expansion to other birth defects, including cardiac anomalies, until 1999 when the UBDN became a full surveillance system collecting all major structural malformations, except ventricular septal defects. All potential cases are reviewed by the Director and a pediatric geneticist for classification of isolated versus multiple defects and etiology if known. Demographic data obtained on each case will provide the Bureau of Children with Special Health Care Needs with information about clinic access, distribution by subspecialty.

The Utah Birth Defect Network (UBDN), a program in the CSHCN Bureau and part of the Teratology and Birth Defect Program, is currently funded through the Centers for Disease Control and Prevention (CDC) and a NICHD grant through Utah State University for a research project on cleft lip and palate. The UBDN is one of nine Centers for Birth Defects Research and Prevention, along with CDC, participating in the National Birth Defects Prevention Study, a large-scale case-control study investigating risk factors involved in birth defects with unknown etiology.

The UBDN leads the Utah Folic Acid Council educating women and health care providers statewide about the importance of multivitamin with folic acid consumption for birth defect prevention. The UBDN annually evaluates the effectiveness of the folic acid prevention activities on NTD prevalence rates for Utah. These data enable the state to plan for needed health services for families of children with birth defects. The UBDN is charged with both primary prevention, as well as recurrence prevention of NTDs. Through a small grant from the local Utah Chapter of March of Dimes with matching funds from Baby Your Baby (Medicaid) the UBDN Director trained WIC staff about folic acid preventable NTDs and provided multivitamins with folic acid to all non-pregnant WIC participants beginning December 2000. In addition, the UBDN obtains valuable information from the Behavioral Risk Factor Surveillance Survey (BRFSS), which queries women in their childbearing years about folic acid awareness, knowledge and consumption. The UBDN utilizes these data to determine focused prevention activities for the state.

Over one-third of infants born with a structural malformation qualify for Medicaid and less than 20% meet the criteria for entry into the Early Intervention Program. In a focus group conducted with the Utah Chapter of the March of Dimes, the UBDN Director met with families to identify issues and barriers of having a child with a birth defect. All families stated that there was an information gap for their particular situation, both prior to delivery and after birth of a child with a birth defect. Families would prefer to discuss pertinent issues or ask questions they may have with another family that has experienced similar challenges. Information provided to them by their health care provider was viewed as inadequate. The Utah Birth Defect Network has the capability to link families to families that share a common bond of having a child with a particular birth defect. This request has come numerous times via focus groups and parents who contact the UBDN. Health care providers are not able to provide the day-to-day information that families would prefer in order to assist their child.

The UBDN provides statewide education for women and health care providers regarding birth defect prevention. The majority of women in their childbearing years do not consume a multivitamin with folic acid. Awareness of folic acid, an important B vitamin, and knowledge that folic acid prevents birth defects do not lead to multivitamin consumption. Women are more likely to consume a multivitamin with folic acid if they hear from their health care provider or clinic staff

about the importance of taking a multivitamin. Because each year there is a new cohort of women entering their childbearing years, statewide educational activities must continue.

The UBDN provides a semiannual newsletter to family physicians, obstetricians, midwives, physician assistants, pediatricians and hospital staff throughout the state. This newsletter provides the latest information about birth defects, prevention activities and concerns. The January 2005 issue was dedicated to topics about NTDs and folic acid. The July 2004 issue provided information to health care providers about the West Nile Virus, CDC recommended protocol for testing, and contact information.

The recent concern in 2004 for West Nile Virus provides a very good example of the ability of the UBDN to respond. With the anticipated WNV epidemic in Utah, the UBDN Director created a WNV Working Group to establish a communication network between the Bureau of Epidemiology, State Laboratory, Department of Pediatrics, Pregnancy RiskLine and the UBDN to monitor any pregnant woman with symptoms, test results and pregnancy outcome information. There is no human information on the impact of WNV in pregnancy, but because it is anticipated to cause central nervous system abnormalities in the fetus, monitoring potential incidences with a well-established birth defect surveillance system requires little additional effort. An anticipated 45,000 women could potentially be exposed at any time in their pregnancy should the WNV impact the state in 2005. Although the number of women that would become infected and transmit the infection to the fetus is not known, the WNV Working Group will be able to assist health care providers pre- and postnatally. A protocol has been written for the postnatal evaluation of any infant known to be prenatally or thought to be postnatally infected.

The UBDN provides a training environment for interested graduate and medical students to study birth defects and work on epidemiologic projects. The UBDN has expertise in epidemiology, dysmorphology, genetics, and molecular genetics through its collaboration with the University of Utah Health Sciences Center, and nutrition epidemiology with the collaboration of Utah State University.

The UBDN Director is a founding member of the National Birth Defect Prevention Network and is the president of this organization for 2005. This group is a collective effort of those individuals and surveillance programs interested in the primary prevention of birth defects, secondary prevention by assisting families with services and research.

In order to coordinate SIDS counseling and education to reduce risk, the Division works with local health departments to serve families. SIDS efforts are coordinated at a state level to build infrastructure for ready access to confidential information and to provide opportunities for collaboration, accurate and complete data collection and analysis, and education. The SIDS Program collects information on SIDS and infant deaths due to asphyxia from public health nurses who gather the information during their contacts with the family. The state assumes the responsibility for maintaining and analyzing the data related to SIDS to develop new strategies or identification of target populations based on data. SIDS deaths are reviewed with the Child Fatality Review Committee to identify policy issues and preventive aspects, enabling the Child Health Nurse Consultant to identify factors related to SIDS deaths, and develop prevention strategies to reduce their risk.

The Violence & Injury Prevention Program (VIPP) promotes the health of all Utah residents by working to reduce the incidence and severity of fatal and non-fatal injuries. This work is done by: 1) data collection and injury epidemiology; 2) education to increase awareness and change behavior; 3) promoting the passage and enforcement of rules, regulations, and legislation to increase safety, e.g., primary seat belt law, graduated driver licensing, school zone speed limit

enforcement, etc.; 4) promoting the use and improvement of safety systems and equipment to reduce injury incidence and severity, e.g., use of seat belts, bicycle helmets, smoke detectors, etc.; 5) coordination and collaboration among community agencies and organizations involved in injury prevention; and 6) strengthening local health department injury prevention capacity.

The VIPP is responsible for injury data collection and analysis, and for tracking, developing, and implementing injury prevention strategies for both unintentional and intentional injury. The Program, which began in 1984 with investigation of school-related injuries, and has evolved from a program with one part-time staff member to one with numerous staff addressing many aspects of both unintentional and intentional injury prevention. The VIPP is funded with MCH Block (in which a majority of the funds are contracted to local health districts), Preventive Block, Rape Prevention Education Grants, Core Injury Surveillance Grant, Traumatic Brain Injury Surveillance Grant, and some categorical grants.

Some of the programs and issues addressed by the VIPP include: child fatality review, domestic violence prevention and fatality review, student injury reporting system, traumatic brain injury surveillance and prevention, fall prevention, motor vehicle occupant injury prevention, pedestrian & bicycle safety, Utah SAFE KIDS Coalition prevention activities, rape & sexual assault prevention, and suicide prevention.

In addition to continued education and community-based activities, there is a need for a primary seat belt law, a bicycle helmet use law and increased enforcement of child restraint laws. Program staff, as well as community partners, has found it very difficult to pass injury prevention laws at this time. Education of legislators and the public will, in time, change the political climate and attitude toward safety legislation for children. There is need to continue to expand the successful methods which have been demonstrated in communities throughout the State. Education about the importance of and the correct use of occupant restraints, especially child safety seats and booster seats, and bicycle helmets needs to continue to further reduce preventable deaths due to lack of or incorrect use.

The Violence and Injury Prevention Program has supported the Utah Youth Suicide Study and the Utah Youth Suicide Prevention Task Force. Although there have been numerous studies that identify causes and contributing factors as well as treatment and intervention for those who attempt suicide, little is known about early identification and effective prevention measures for teens who may be at risk for but have not yet attempted suicide. The findings of the Youth Suicide Study need to be applied in planning, implementing and evaluating prevention strategies for high-risk youth. The Utah Youth Suicide Task Force, a multi-disciplinary team that addresses the serious problem of youth suicide in Utah, consists of members from the University of Utah, Department of Health, NAMI Utah, Mental Health Association of Utah, Division of Youth Corrections, State Office of Education, State PTA, Brigham Young University, legislative fiscal analyst, Juvenile Court, and other agencies. VIPP staff assists this task force by provision of data analysis, assistance in writing the “Suicide in Utah” report, assistance in planning activities and evaluation of suicide prevention efforts. The youth suicide prevention effort will be transferred to the new children’s mental health specialist position so that VIPP can focus its work on surveillance.

Violence and Injury Prevention Program works with its partners to educate the public about the need for appropriate locked and unloaded firearms storage. VIPP promotes the ASK Campaign (Asking Saves Kids), which is a national campaign that encourages parents to ask their neighbors if they have a gun in the home before sending their children to that home to play. Local health departments conduct educational programs such as "Gunwise" utilizing Title V funding to make parents aware of their personal responsibility for proper storage of guns in their homes.

Approximately 80% of all adult tobacco users start smoking before the age of 18. Every day, nearly 4,000 young people under the age of 18 try their first cigarette. More than 6.4 million children living today will die prematurely because of the decision to smoke cigarettes. In 2003, more than 13,000 Utah students in middle and high school reported being regular cigarette smokers. Approximately 60% of the high school smokers indicated that they wanted to quit. While a variety of effective adult cessation programs were developed and tested during the past decades, addressing nicotine addiction among youth remains a challenge.

Through a combination of retailer education, positive recognition and compliance checks, successful tobacco buy attempts by underage youth during compliance checks have been reduced from 60 to 70% in some areas in the mid-1990s, to less than 10% statewide. The 2003 Utah Youth Tobacco Survey found that more than 70% of current high school smokers list social sources as their most frequent way of obtaining cigarettes. Tobacco control programs need to research and carry out interventions that aim at reducing minors' access to tobacco through buys as well as social sources.

In the past couple of years, the Bureau of Health Promotion in the Division of Community and Family has developed several new programs, which include children's health needs. The Asthma and the Genomics Programs have been created to provide state-level planning to address needs of Utah's population including mothers and children. MCH staff members are involved with these programs as they develop strategies to address these areas. In addition, other Bureau of Health Promotion programs provide prevention services that include children, such as Diabetes Program and Heart Disease and Stroke Prevention Program. The Bureau of Health Promotion is launching a major effort to reduce childhood obesity. Title V funding supports some of the Bureau's efforts in this campaign and Title V staff members, including the Title V Director, MCH Director and CSHCN Director, are actively partnering in their efforts.

New efforts that the Title V agency will be involved with include mental health and obesity. The Division has recently hired a Children's Mental Health Specialist who will be working on prevention and early recognition of mental health issues for children and postpartum women. Although mental health doesn't fall under the purview of the Utah Department of Health, the needs assessment had identified mental health as an area of concern for all three of the Title V populations. The Children's Mental Health Specialist will work with the Division of Substance Abuse and Mental Health and others to promote an appropriate Title V role in this important health issue.

In addition, Title V staff will join the efforts of the Bureau of Health Promotion in working to reduce obesity in children. While YRBS data indicate the Utah youth are below the national average for obesity, programs within the Division recognize obesity as an emerging issue based on the increasing trend in obese youth. The Bureau of Health Promotion through the Gold Medal School initiative has targeted elementary schools across the state. Program staff has started discussions of ways to collect data statewide and expand prevention efforts. The program has enrolled 40% of elementary schools (190) in the program, with 31% (148) currently participating. Another 42 schools have participated and the program staff is working to re-engage them with the Gold Medal Plus program. The program expects to enroll 80% of elementary schools in the Gold Medal Program by 2008, including 90% of title I schools.

State's coordination with other agencies and organizations (e.g. universities, managed care organizations, provider groups, etc.) in the provision of population-based services

Baby Your Baby coordinates with many different groups through its Advisory Board, consisting of representation from Intermountain Health Corporation, the state's largest health care system, KUTV, the local CBS affiliate, and others. The Advisory Board meets regularly to provide input to the Department on priorities and mechanisms to accomplish them. Baby Your Baby staff provides coverage for the Baby Your Baby Hotline as well as other Department of Health hotlines, such as the Immunization Resource Hotline, Health Resource Line (which is a general health resource for information about community resources), Cancer Control hotline, and the Children's Health Insurance Program (CHIP) and Primary Care Network (PCN) hotlines. Each hotline has an advisory committee or board with which the Department coordinates efforts. In addition, the Department also has a BabyWatch/Early Intervention Hotline that is operated separately from the others.

The Maternal and Child Health Bureau partners with a number of key organizations and institutions to carry out its work, such as the Intermountain Pediatric Society collaborative quality improvement effort, the state Primary Care Association – AUCH – Association for Utah Community Health, March of Dimes on their Prematurity Prevention Campaign, Planned Parenthood Association of Utah around family planning service gaps, local health departments and community health centers, the state Division of Substance Abuse and Mental Health on mental health service gaps, and so on. The Bureau and its programs have a number of committees, advisory committees, councils that address health resources for mothers and children, including those with special needs, including the Intermountain Pediatric Society (Utah Chapter of American Academy of Pediatrics, American College of Obstetricians and Gynecologists, Association of Women Health Obstetric and Neonatal Nurses, and American Academy of Family Physicians. The Division is heavily involved in an effort through the Early Childhood Council (ECC) to develop a statewide system of comprehensive services for young children and their families that includes early childhood development and education, parent support and health and well-being. The ECC is composed of a diverse group of individuals representing all aspects of the spectrum of early childhood needs.

MCH Bureau staff has worked with the Office of Vital Records and Statistics to provide input in the development of the new birth certificate to be implemented in 2007. MCH Bureau staff has sought input from outside partners in order to ensure that the new birth certificate includes data fields that are used to identify factors associated with pregnancy outcomes and to develop program strategies to improve them.

CFHS has met with the Bureau of Communicable Disease to discuss partnership on issues related to STDs, HIV/AIDS, and teen pregnancy prevention. The Bureau of Communicable Disease is in a sister division of the state, thus collaboration is important in moving forward on these areas that impact women of reproductive age and youth. The Reproductive Health Program has collaborated with the Bureau of Communicable Disease on prevention of Perinatal HIV/AIDS through an Action Learning Laboratory in 200X sponsored by AMCHP. Although the Action Learning Laboratory Project is completed, RHP continues to work with the Bureau of Communicable Disease to prevent the spread of HIV/AIDS.

The Utah Immunization Program regularly coordinates and collaborates with managed care organizations, public and private providers, community health centers, and Medicaid in the provision of statewide services, outreach, and education. The Utah Immunization Program has a strong relationship with Medicaid to provide vaccine to eligible children ages birth-18 through the VFC program, and to coordinate vaccine management issues and support for private and public providers. The Immunization Program coordinates with Medicaid to support the media campaign

for public education on vaccine issues targeting the birth-2 year old age group. Since WIC linkage activities are mandated on a federal level, coordination with WIC allows immunization education, outreach and access activities at WIC clinics statewide. The Utah Immunization Program coordinates with major providers of health-related services such as American Academy of Pediatrics, Utah Medical Association, community health centers, managed care organizations, and Children's Health Insurance Program (Utah's CHIP Program). The program supports the Every Child by Two Taskforce with the goal of education, increased access and rates for children during the first two years.

The State Scientific Vaccine Advisory Committee was first convened in 1999 to provide a forum for some scientific input to the priorities and policies of the Immunization Program. Members of the committee include representatives of local health departments, state epidemiology, family practice and pediatrics, a medical communicable disease specialty, and Medicaid. The committee meets quarterly to review recommended practices and provide recommendations to the state as to necessary actions. The most recent recommendation of the Vaccine Advisory Committee to the state was a mandate for child care and school entry vaccination with Varicella and Hepatitis A. At this point, the Immunization Program is evaluating the ability to provide these vaccines for these children if the mandate were implemented. It looks unlikely that the recommendation for Varicella will be possible at present because of vaccine cost and available resources. The recommendation for Varicella and Hepatitis A for school entry was implemented into law July 1, 2002. Continued collaboration with these partners is vital to the program, as is the identification of new public/private partnerships to support the immunization registry and outreach and education efforts to improve Utah's immunization rates.

The Utah Birth Defect Network is well integrated with perinatal providers, genetic counselors, and specialty pediatric providers throughout the state. The UBDN works closely with the University of Utah Health Sciences Center, Intermountain Health Care, Primary Childrens Medical Center, the Utah Chapter of the March of Dimes, and the Utah Perinatal Association.

The Pregnancy RiskLine has a close relationship, in fact, a partnership, with health care professionals at the University of Utah Health Sciences Center. For example, one of the leading supports for the RiskLine and its work is a medical geneticist at the University. In addition, there is a strong collaborative relationship with a medical bioethicist, etc. It is anticipated that this relationship will be strengthened with the recently awarded Genetic Services and Data Integration Grant from the Maternal and Child Health Genetic Services Branch grant and the reconstitution of the Department's Genetics Advisory Committee.

To reduce injuries among Utah children, the Violence and Injury Prevention Program (VIPP) collaborates with many partners including other Department programs, state and local agencies, local health departments, businesses, as well as non-profit community organizations, health care providers and others. These relationships include working to enhance injury programs by freely sharing expertise, volunteering to participate in their activities when appropriate, sharing resources, etc. VIPP has formed working partnerships with Brain Injury Association of Utah (BIAU), Coalition for Utah Traffic Safety (CUTS), Emergency Medical Services for Children (EMSC), Intermountain Injury Control Research Center (IICRC), law enforcement agencies, media, Poison Control Center (PCC), Primary Children's Medical Center (PCMC), Rape Crisis Center Directors, Salt Lake County Bicycle Advisory Committee, school districts statewide, Utah Coalition Against Sexual Assault, Utah Department of Public Safety (UDPS), Department of Transportation (UDOT), Domestic Violence Council (UDVC), Driver and Traffic Safety Education Association, PTA, Utah Safe Kids Coalition, Utah Safety Council, and the Utah Substance Abuse

and Violence Prevention Council.

The interagency Child Fatality Review Committee (CFRC) was established in 1992 by the VIPP, under the auspices of the Utah Department of Health. CFRC brings together the many diverse agencies and organizations that serve Utah children and families, with the goal of better understanding of the causes and circumstances of child fatalities to prevent future deaths. Committee representation includes the Medical Examiner's Office, Office of Vital Record and Statistics, Emergency Medical Services, Department programs, State Office of Education, Attorney General's Office, Administrative Office of the Courts, Department of Human Services' Administrative Office and Division of Children and Family Services, Valley Mental Health Center, local law enforcement agencies, Criminal Justice, Primary Children's Medical Center, and others. This multi-disciplinary committee reviews all available information on child deaths in order to identify and describe: 1) prevalence of risk factors among deceased children; 2) trends and patterns of child deaths in Utah; 3) response of service systems to high-risk children; 4) preventable deaths and strategies to reduce the number of child deaths; 5) accuracy and completeness of information on death certificates; and 6) strategies to improve the quality of care to the child and family through provision of professional and community education. The CFRC also works to assure complete and thorough investigations are performed on all child deaths, to maximize resources through collaboration, and to make policy recommendations to improve the system response.

VIPP collaborates with other MCH programs, such as Child Adolescent and School Health and Reproductive Health. VIPP also contracts with LHDs to provide most of the community level injury prevention activities.

Geographic availability/distribution and funding of population-based services

Currently, Utah screens for five diseases in newborns, including phenylketonuria, galactosemia, hemoglobinopathies, hypothyroidism and newborn hearing loss. During the 2005 Legislative Session in Utah, with the collaboration of numerous advisory groups, UDOH newborn heelstick kit fees were increased to allow for the expansion of newborn screening options. The Utah Genetics Advisory Council approved the expansion of state mandatory testing to include the diseases screened for by tandem mass spectrometry as well as congenital adrenal hyperplasia and Biotinidase, which will increase the number of conditions to be screened to 36. These changes were facilitated by a successful pilot program to assess feasibility of testing with the University of Utah Health Sciences Center, Department of Health (laboratory and follow-up) and a private laboratory, Associated Regional and University Pathologists, Inc. (ARUP). This unique partnership will continue as a collaborative effort in the implementation of these dramatic changes.

In July 1999, the Utah State Legislature enacted a law requiring all birthing facilities to implement Universal Newborn Hearing Screening (NHS) programs. UDOH, in collaboration with the National Center for Hearing Assessment and Management (NCHAM) housed at Utah State University, implemented a computer-based tracking and data management system. The "Hearing Impaired Tracking" (HI*TRACK) system has fields for over 200 variables related to demographic, medical, and contact information for the baby and mother, results of screening and diagnostic measures, and status relative to diagnosis and intervention. The UDOH CSHCN Bureau collects the results of screenings and specific demographic data from all 43 Utah birthing hospitals and birthing centers, and Primary Children's Medical Center. These data are collected on a monthly basis for each baby born**.** The HI*TRACK system allows case management and follow-up on all babies who fail the initial screening, tracking through diagnosis, and enrollment in an appropriate

early intervention program. CSHCN provides training and support to all of the NHS programs and the birthing hospitals through training and monitoring of quality of the screening process.

Newborn heelstick screening is available in every birth institution (including hospitals and birthing centers) in the state and through providers who do home deliveries and medical home providers. Identification of abnormal results and the arrangements for further testing if needed is coordinated with the medical home providers and medical specialists. Program funding is generated through the purchase of screening kits by the birth institutions and providers.

WIC services are available statewide through local health departments and one specialty clinic for teens. In FY04, there was only one rural clinic closure due to low participation numbers, with resultant cost savings by transferring participants to another clinic location. Overall, the availability of WIC clinics in rural and urban areas is considered sufficient at this time.

Access to the services provided by the Pregnancy RiskLine is facilitated statewide through the program's toll-free telephone service. Consumers, as well as health care professionals, call Pregnancy RiskLine if they have questions about potential impact of an exposure on a pregnancy. These services are available to callers during regular business hours; however, the program has an answering machine that enables program staff to return calls to callers who have accessed the program during non-business hours. Pregnancy RiskLine staff also provide many educational presentations to community and health care provider groups across the state. The Utah Abstinence-only Education Program is the state's federally funded program that resulted from the 1996 federal welfare reform legislation. The Utah Program focuses on abstinence-only projects for youth (both boys and girls) between the ages of 9 and 14 years. Eight community-based projects include, but are not limited to, programs that promote self-esteem, self-confidence and healthy decision making, and resisting pressure to become involved in sexual activity; prevention of sexual abuse including date rape; communication between parents and youth and parent training on abstinence; and programs that target high-risk youth. Projects are required to follow the federal definition of abstinence education and include a parent component and an evaluation plan. The projects are located in various communities in the state through local health departments, school districts and private not-for-profit organizations.

Community-based injury prevention programs are available in each of the twelve local health departments (LHDs) through contracts from the Violence and Injury Prevention Program (VIPP). These prevention programs address injury prevention throughout the State. While individual LHDs are encouraged to base their injury prevention plans on the unique needs of their local communities, all are required to include at least one major component that addresses motor vehicle crash injury prevention including occupant protection, bicycle safety, or pedestrian safety. For the past five years, all LHDs have been participating in the implementation of a statewide effort to survey and improve booster seat use among children age 4-8 years.

Funding mechanisms for population-based services

The MCH Block grant provides the bulk of funding for population-based services provided for mothers and infants. Numerous programs, as mentioned in the State Overview section, are funded with MCH Block Grant dollars, enabling the state to address the health care needs for mothers and children. Programs usually have more than one funding source, such as state general funds, Preventive Block Grant, other CDC grants (PRAMS), other HRSA grants (SSDI, SECCS, etc.), USDA, the Administration for Children and Families (Head Start State Collaboration Project and Abstinence Education), the tobacco master settlement fund, private grants, and so on. The

blending of funding from various sources maximizes the state's ability to develop population-based services.

Infrastructure Building Services

State's capacity to promote comprehensive systems of service

The Utah Department of Health has made great strides in infrastructure building services for addressing health issues for women of childbearing ages, children and youth, and children and youth with special health care needs. Data analytic capacity, database integration, adolescent health, medical home, collaborative efforts on key issues for mothers and children have all developed during the previous five years. With the formal five-year needs assessment coming to a culmination, the Department has identified new priorities for the upcoming years and has reallocated some of its Title V block grant funding and staff time in order to address the priorities.

Utah submitted an application for the MATRICHS analytic training program, offered by the University of Rochester. The UDOH application was selected as one of fifteen states to participate in the program for 2005-2006. The program, which includes nine months of educational experience through online modules and site visits by the faculty, will provide Utah MCH with an opportunity to enhance its data and analytical skills. The Utah team includes the director of family health services in the Salt Lake Valley Health Department, which will provide both agencies with an opportunity to work together on the issue of adequacy of prenatal care. One component of MATRICHS that is particularly attractive is that the faculty conducts two on-site training opportunities that include staff beyond the team participating in the program, thus enabling the Title V agency to promote the enhancement of data skills to others in the agency. Teams that complete the MATRICHS training will become a resource within their agency and state.

The MCH Bureau, along with the Reproductive Health Program, formed a Perinatal Task Force to address issues related to pregnancy, pregnancy outcomes and reproductive care. The members of the Task Force identified four priority areas: prenatal care, pregnancy spacing and intendedness, prematurity and low birth weight, and postpartum depression. Workgroups have been formed for each priority with the expectation that recommendations will be made to address each of the issues. For example, Utah's prenatal adequacy is low compared to other states, a concerning issue. A couple of years ago we conducted a mail in survey of obstetrical providers (OBs, family practice, CNMs) on their policies regarding entry into prenatal care. The majority responded that their practice was following the ACOG guidelines for prenatal care entry and visits. However, increasingly we are hearing that prenatal care providers are holding off the first prenatal visit until after 12 weeks. We will continue to develop mechanisms to accurately evaluate the extent of the problem in Utah.

PRAMS data have been very instrumental in providing insight into gaps in comprehensive systems of service in Utah. We currently have five years of data from which to analyze questions related to MCH issues of concern. To date, we have published numerous reports that have been widely disseminated throughout the state to healthcare providers, community health and non-profit partners; topics include "Adequacy of Prenatal Care", "Unintended Pregnancy", "Tobacco Use", "Breastfeeding", "Prenatal Education" and "Prematurity". Utah PRAMS data are available on the "Indicator Based Information System" (IBIS) in queriable format. In addition, a comprehensive data book containing most of the data collected by PRAMS has been published and disseminated to appropriate individuals and organizations throughout the state.

The Department of Health has been integrally involved in a state level coalition targeted to build infrastructure for an early childhood service system, the Early Childhood Council. The Council brings together over thirty state and local programs and advocacy and non-profit organizations interested in promoting an early childhood services. Division staff serves on the Early Childhood Council and its Executive Committee. The Title V Director, MCH and CSHCN Directors, other Title V staff and the Head Start-State Collaboration Office Director collaborate with Voices for Utah Children, the Utah Family Center, the Utah Parent Center, the Head Start Association and other organizations on the Early Childhood Council and on specialized projects, including the Utah Kids Count Data Book. The Council has been involved in discussions centered on the need for and the development of more integrated systems of multi-agency early childhood services. The Council now serves as the advisory committee for the State Early Childhood Comprehensive Systems grant.

The State Early Childhood Comprehensive Systems (SECCS) Grant is supporting the existing Early Childhood Council to build infrastructure for the system of services for young children. The Title V, MCH and CSHCN Directors have been strong partners in the Early Childhood Council ensuring that improving the health and mental health of young children are included in the Council's goals and objectives. Additionally, the MCH needs assessment process has provided another mechanism for gathering and confirming information related to gaps and needs for the system of services for young children.

Infrastructure building for the system of services for young children extends beyond state-level initiatives. The Head Start-State Collaboration Office provides funding for six local early childhood councils that cover all regions of the state. These councils are addressing local issues including literacy, provider training, and service coordination for local providers. One local council is assisting in the coordination of services among pediatric practices, Early Head Start, Early Intervention, and other service providers for children with developmental delays. The members of this local council have provided technical assistance to pediatric practices on identifying developmental delays and have gathered information about ways other service providers can better meet the needs of pediatric practices.

The Division has collaborated with many other programs and agencies in and outside the Department of Health to improve access to important health and safety training for childcare providers through the federal Healthy Child Care America (HCCA) Grant. CFHS has developed partnerships with a many agencies and programs involved in Utah's childcare system to develop the Utah Health and Safety Training Curriculum for Early Childhood Providers'. Trainings are available through the local Child Care Resource and Referral agencies in collaboration with local health departments. The Division recently hosted a meeting of HCCA representatives from several neighboring states to discuss training strategies and ways to promote the role of the Child Care Health Consultant. This meeting for regional Healthy Child Care America grantees led to collaborative efforts among the Office of Child Care, the Bureau of Child Care Licensing and the Child Adolescent and School Health Program to hire a full-time Child Care Health Consultant to work in one of Utah's metropolitan areas, Davis County.

The Presumptive Eligibility Program for Prenatal Medicaid continues to screen pregnant women throughout the state. To increase access to presumptive eligibility for pregnant women, three new eligibility sites have been added in the past 3 years in the Salt Lake Valley area, with the anticipation that 12 additional sites will be added in 2005, nine of which will be in rural areas. To promote more widespread access, CFHS has contracted with Utah State University's Early Intervention Research Institute to develop a web-based application system, which will also include

Medicaid, WIC, Children with Special Health Care Needs, and Early Intervention. The online system will be available in English and Spanish. Improved Access to multiple services essential for low-income families, especially those with low-incomes, will be improved despite the usual barriers of transportation, childcare and available hours.

Perinatal care coordination for presumptively eligible pregnant women is available through Medicaid qualified providers (QP) who assess possible risks that may impact pregnancy outcomes. The QPs determine women's risk status by medical and obstetrical history, including lifestyle behaviors, and psychosocial stressors, with appropriate referrals to Medicaid-covered services for home visiting, psychosocial and nutritional counseling and childbirth education classes. Local health departments in the Wasatch Front are encouraged to work with the Managed Care Organization care coordinators. Two RN case managers in the Reproductive Health Program provide case management for high-risk prenatal women in Salt Lake County for Intermountain Health Care's Medicaid product, IHC Access. Local health departments are encouraged to provide services to women who are not Medicaid eligible through their Prenatal to Five Home Visiting Program funded with Title V contracts to the local agencies.

The Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ), sponsored by the Intermountain Pediatric Society, Utah's chapter of the American Academy of Pediatrics, the state Title V and Title XX agencies, the University of Utah Pediatrics Department, and other key health organizations are providing training to pediatric practices to improve the quality of services delivered in pediatric provider practices. The MCH Director, SECCS Grant Director, and Children's Mental Health Prevention Specialist have been involved in guiding and supporting the work of UPIQ to improve well-child services, developmental screening, and social emotional screening of young children.

The Department has built state infrastructure for adolescent health by completion of the report (How Healthy are Utah's Adolescents?), creation of an Adolescent Health Coordinator position, organizing an Adolescent Health Advisory Committee, and pilot testing AMCHP's Adolescent Health System Capacity Assessment Tool. The Adolescent Health Advisory Committee determined mental health issues to be the top priority for the adolescent population. The committee provided input on developing the adolescent portion to the CASH website and in purchasing mental-health related outreach materials for parents and adolescents.

The "Survey about Health Concerns for Utah Mothers and Children" identified after school supervision as a major issue for children in Utah. Understanding the relationship between unsupervised out-of-school time and violence, teen pregnancy, substance use, and other adolescent issues, the Child Adolescent and School Health (CASH) Program has been involved in after school issues. The Program Manager is involved in supporting efforts to build quality after school programs through membership on the AfterSchool Utah Board. This board brings together seventeen organizations that work with out-of-school-care issues including school districts; private providers; the Boys and Girls Club; Parks and Recreation; Child Care Resource and Referral agencies; the Office of Child Care; and the Utah Association for Adult, Community, and Continuing Education. AfterSchool Utah and the Office of Child Care have applied for a Mott Foundation grant to improve the system of services for out-of-school care. Additionally, AfterSchool Utah and the Utah State Office of Education partnered to host a three-day Think Tank in January 2005 to identify gaps, needs, opportunities, and strategies to improve the system of out-of-school care and adult continuing education for Utah

The Utah Collaborative Medical Home Project is a collaborative effort by the Bureau of Children with Special Health Care Needs with the University of Utah Department of Pediatrics,

Utah State University, Medicaid and Utah Family Voices that provides outreach and support to medical homes statewide for children with special health care needs (CSHCN) in primary care settings. Originally funded by an MCHB grant, the project continues to expand throughout the state and is guided by a broad-based advisory committee composed of private pediatric and family practice physicians, families, allied health professionals and other state partners, such as Education, Vocational Rehabilitation and Medicaid. The strategic plan for children and youth with special health care needs for Primary Children's Medical Center (PCMC) includes an action step to support medical homes. The CSHCN Director serves on the PCMC Pediatric Education Services Continuing Medical Education Committee, the credentialing committee for CME credits for physicians. This Committee identifies the topics to be presented in weekly Pediatric Grand Rounds statewide.

Through the Utah Integrated Services grant, awarded to CSHCN by HRSA MCHB in Spring 2005, the CSHCN Bureau will emphasize its work in the development of population-based services and infrastructure development over the next five years. The Medical Home Initiative in Utah has been instrumental in improving the capacity of primary care providers to serve children and youth with special health care needs. Expansion of this initiative to more practices will be critical to support children and families. Advances in health care technology are allowing children with complex and chronic conditions to live longer. Prematurely born newborns are surviving at lower birth weights and gestational ages, but often with higher morbidity. The Bureau of Children with Special Health Care Needs will continue to partner with tertiary care hospitals and with community partners to support these children and families. Through the grant, all six 2010 Core Outcomes for children and youth with special health care needs will be addressed, with emphasis on transition to adulthood, early and continuous screening, and Medical Home. As part of the grant, learning collaboratives will be conducted which will expand Medical home information and training.

The Division is fortunate to have strong Department leadership related to core public health functions and infrastructure to support these functions. The Department has developed a strong commitment to collection, analysis and dissemination of data. Since the 2001 needs assessment, the Department created the Center for Health Data, which includes several offices, including Vital Records and Statistics. Division staff works closely with staff from Vital Records, as well as staff from the other Center Offices. Division staff members contribute to the IBIS website, an Internet query system which includes vital records, hospital discharge, PRAMS, BRFSS and population data sets.

Over the past five years, the UDOH has made substantial progress in developing public health information infrastructure that integrates health data systems. The Child Health Advanced Record Management (CHARM) system will create a virtual health record for every child that allows real-time data sharing across health programs and medical homes. Funds for this data integration initiative have come from the EHDI Cooperative agreement, the Genetic Services Implementation (MCH - GSDI) grant, the MCH State Systems Development (SSDI) grant and the Title V Block Grant.

Phase I of this statewide system, to be completed by July 2005, links vital records (birth and death certificates), the Utah Immunization Registry, and EHDI (the Newborn Hearing Screening) databases. Phase II begins July 2005 and will link databases from the Newborn Screening (Heelstick) Program, Baby Watch/ Early Intervention, and the Birth Defects Network, and provide web access. Each participating program maintains its own database and controls what data are shared and with whom based on formal Data Sharing Agreements. The goal of integrating health

information among these programs is to improve health care by providing more complete information to the medical home and families. The statewide system will reduce the number of children who are lost to follow-up, reduce duplication of health care services, such as immunizations, allow more accurate tracking of adoptions, babies with name changes, and will provide consistent, current, and authoritative information about any child born in Utah or any child who is receiving services from one of the participating health care programs. Access to this system will also alert users to exceptional conditions in individual children. Future plans for the system may include additional program data integration, such as Children with Special Health Care Needs and secure access linking and transmission to providers, using the MedHome Portal website.

Efforts are currently ongoing to improve data quality (e.g. accuracy, completeness, timeliness) of the child health information that is used to integrate the health care services provided by UDOH programs, private providers, hospitals, and clinics. The Child Health Advanced Records Management (CHARM) will provide an easy to use, technology based way of providing access to integrated information at the point of service. The CHARM system will act as an electronic broker for participating programs, but it will not replace existing databases.

The SSDI Project supports the continuation of the CHARM Project and enhances its data quality The project furthers the probabilistic linkage of vital records with Medicaid eligibility files, hospital discharge with vital records, hospital discharge with PRAMS, and possibly WIC data with vital records and YRBS. CHARM's Data Related Rules and Policy Thread Team (DRRPT), in the past called NCHARM (Newborn CHARM), supports the goals and objectives of SSDI. The DRPPT will ensure that data are collected, stored, shared and utilized by all the stakeholders in a non-discriminatory manner, in accordance with state and federal laws and with family input and consent, to improve the accuracy, completeness, timeliness and reliability of the data collected while making it readily available to all stakeholders in a confidential, secure manner.

Other data integration activities that Title V agency is involved in include bridging WIC and USIIS data bases to enable WIC clinic staff to assess a children's immunization status, IBIS in which MCH staff contributes content on specific health areas, such as prenatal care, low birth weight, child health issues, etc. IBIS has evolved into a tool that is useful to DOH staff as well as the public for accessing data from a variety of sources of the DOH, including birth and death records, hospital discharge data, survey data, such as BRFSS, PRAMS, Health Status Survey, etc. The web address for this resource is http://ibis.health.utah.gov.

The state Medicaid agency has developed a data warehouse that affords access to Medicaid data by key data staff in the Department. However, the limitation of the data warehouse is that it does not currently include the managed care organization (MCO) data, which includes the majority of the Medicaid population in the state. Medicaid is working with the MCOs to obtain their data to be inclusive of all Medicaid participant data.

The Data Resources Program in the MCH Bureau participates in several data integration efforts, as well as with the Department's survey unit to provide input on data needed on women of childbearing ages and children that are not available through other sources.

WIC is in the finishing steps of completing conversion of its current DOS-based information system to a Windows based system. The new information system should be implemented in local clinics late summer. In addition, the Utah WIC Program is involved in a three-state consortium to develop a new information system that may become a national model for WIC information systems. Utah WIC staff is working with Colorado and Wyoming on this USDA-funded project.

Utah CSHCN is in its third year of the MCHB-funded Utah Leadership Education in Neurodevelopmental Disabilities (ULEND) Program. Through ULEND, CSHCN is collaborating with Utah State University, Center for Persons with Disabilities and University of Utah, Department of Pediatrics, School of Medicine, in an MCHB Leadership Grant. ULEND provides opportunities for students and professionals from a variety of health-related disciplines (e.g. pediatrics, physical and occupational therapy, speech-language pathology, psychology, nutrition, social work, audiology, pediatric dentistry, genetics, nursing, business/marketing, special education, and families) to increase their knowledge and skills in providing services and supports to children with neuro-developmental disabilities. With the growing trend towards collaborative interdisciplinary efforts in the health care field, the demand for persons with enhanced teamwork skills who have had experience working with individuals from a variety of disciplines to provide services to children with disabilities has increased.

The CSHCN Bureau staff participates in Medicaid's Utilization Review and EPSDT Expanded Services Committee that meets weekly to determine coverage of non-covered services for Medicaid recipients. The CSHCN Bureau Director, a pediatric neurologist, has voting status on the committee. The Bureau's physical therapy supervisor is a consultant to the committee.

CSHCN collaborates with other state agencies through numerous initiatives and grants. The Bureau of CSHCN was awarded a CDC grant and has contracted with Utah State University and the University of Utah for Early Hearing Detection and Intervention (EHDI) tracking, research activities, and integration with other newborn screening programs. The 5-year grant was awarded September 30, 2000 to improve the timeliness and appropriateness of early hearing detection and intervention service to infants and their families by 1) refining and expanding Utah's existing surveillance and tracking for EHDI, and 2) integrating the EHDI surveillance and tracking system with other relevant public health information databases and service systems. Application for continuing CDC EHDI support is currently underway. CSHCN also has funding to support data integration activities and the Newborn Hearing Screening Program through a HRSA EHDI grant.

CSHCN was also awarded a Centers for Disease Control and Prevention grant to establish the Utah Registry of Autism and Developmental Disabilities (URADD). In collaboration with the University of Utah Health Sciences Center and with the Utah Office of Education, an epidemiological study is being conducted to determine how many Utah children have Autism Spectrum Disorders and/or Mental Retardation. A key component of the registry is to assist in educating families and service providers about autism and where to access services.

The Utah Genetics Implementation Project (UGIP) facilitates collaboration with Utah Department of Health (UDOH) programs, community and parent advocacy groups and other stakeholders to develop and implement a shared birth record number among newborn screening programs and birth certificates as well as enable development of educational projects and materials regarding medical homes for children with genetic conditions. Additionally, the UGIP assists with the inclusion of the Newborn Heelstick Screening (NHS) program into the UDOH integrated child health data system, the Child Health Advanced Records Management System (CHARM). The UGIP also makes possible the development of a formal, institutionalized system for adding, changing or replacing screens on the NHS panel.

The Bureau of Health Promotion, in the Division of Community and Family Health Services, includes a Genomics Program, which promotes the importance of genomics and its influence on health for the population. The program's website is http://health.utah.gov/genomics. The program is in the beginning stages of defining its role in the Department with plans to hold discussions about direction for the future.

University of Utah School of Medicine Department of Pediatric physicians serve on numerous CSHCN advisory committees, including the BabyWatch/Early Intervention Program Interagency Coordinating Council, the Medical Home Advisory Council, the Newborn Hearing Screening Advisory Committee and the Genetics Advisory Committee.

The CSHCN Director is also involved in University of Utah and Primary Children's Medical Center (PCMC) based Health Services Research Committee. The CSHCN Family Advocate Coordinator serves on the Family Advisory Committee for PCMC.

The State Primary Care Office (PCO) collaborates with the Title V agency on the MCH Advisory Committee and its work. In addition, the PCO staff involves Title V staff in funding proposals to support rural and primary care in the state through its work with local health departments.

The Department has contracted with Utah State University to develop an online application system called Utah Clicks for several programs: Medicaid, Presumptive Eligibility, Early Intervention Children with Special Health Care Needs Services, and WIC. Utah Clicks has recently been pilot tested with all programs except WIC in a large local health department with great success. The WIC online application module has been delayed because it needs to be rolled out at the same time as new WIC Windows System, which should be ready this fall. This system will enable families to apply for services in a much more user-friendly manner from their own homes or other sites where they can access a computer.

The Division has built enhanced data capacity to support MCH and CSHCN programs in their data needs for program planning and evaluation. Since the last needs assessment, the Division created and filled a MCH Epidemiologist position, added additional data staff members that are critical to the work that the Title V agency does. The Division has need for additional data analytic capacity; however, new positions cannot be created even though federal funds are available to do so. The Data Resources Program, headed by the MCH Epidemiologist, has developed in the past two years the capacity to provide data analytical support to the WIC and Immunizations Programs. The Immunization Program Manager who initially did not see a need for enhanced data capacity for her program now wants a full-time staff member assigned to her program. Having a MCH Epidemiologist has enabled the State Title V agency to conduct higher-level analyses of data, participate with outside partners on studies (fetal death study funded by NIH grant to the University of Utah) develop surveys based on sound survey methodology, develop program evaluation plans that contribution to quality improvement of program strategies, etc. In addition, the MCH Epidemiologist provides oversight of data work that others do within the MCH and CSHCN programs, stimulates research and develops abstracts for meetings like the annual MCH Epidemiology meetings.

The Department has also made tremendous strides in the past five years with website development. Every program in the Title V agency has a website that provides the public and professionals with up to date information from program work. The Title V agency has also developed capacity in the area of online application systems, such as a WIC vendor online quarterly price survey that in the past was done with pencil and paper by the vendors and then entered into a database at the state. Now, vendors enter their prices into the online system, which dumps the data automatically into a database, reducing time and efforts.

Overall system of care

The following is a description of health issues/system issues among maternal, infant, child, adolescent and children with special needs populations. Although Utah's fetal, infant and maternal

death rates are relatively low, these deaths are tragic occurrences and some may be preventable. The Perinatal Mortality Review Program (PMR) was developed to review fetal deaths that occur after 34 weeks' gestation; infant deaths due to perinatal conditions identified through vital records, and maternal deaths. The PMR is administered at the state level and enables statewide surveillance of these events. Health and vital records data are collected, summarized, and reviewed by perinatal health care specialists from different disciplines and settings to identify opportunities for prevention. Maternal deaths are identified through a matching of fetal death certificates and birth certificates with death certificates of all women of childbearing ages whose death occurred within one year of the pregnancy termination. Linking of certificates and expansion of the definition of maternal deaths to include those that occur within twelve months of a recorded pregnancy termination have resulted in an expected increase in maternal deaths due to improved case finding. Data for each case are collected and summarized by the Perinatal Mortality Review Coordinator who, with other health care professionals, reviews the deaths to determine if they are directly related, indirectly related or not related to pregnancy. During the review process, recommendations made by the review team are recorded and used to plan interventions for the prevention of future deaths. Collaboration with professional organizations has enabled the Division to promote review findings to providers in order to address provider practice issues. Better consultation and referral networks within the state health care systems would promote better pregnancy outcomes.

In 2003, the Maternal Child Health Bureau organized a Perinatal Task Force, comprised of community members, health care providers, health plan representatives, and Department staff. Staff presented an overview of MCH issues for Utah mothers and infants, such as the declining percentages of women entering prenatal care early. The Task Force members selected four priority areas from a long list of possible issues: family planning, prematurity, prenatal care, and perinatal depression. Subcommittees have been formed to address each of these issues and to date, recommendations for action items have been provided by the family planning subcommittee and the remaining subcommittees are working to do the same.

A number of existing systems currently collaborate to provide health care to uninsured children. These systems and efforts include the managed care system in the provision of services; the Department (CHIP, Medicaid, and MCH programs) in providing outreach to get eligible children covered and in trying to simplify systems; legislators in providing funding; and, administration in providing guidance.

Collaborative mechanisms include regularly scheduled meetings to share information and ideas; data sharing among programs and systems; informal verbal communication and electronic communication; collaboration on the production of outreach materials. The work of CHIP, Covering Kids and Families Project, and Medicaid is very closely tied together with regular communication and cooperation. There are, however, some issues that need to be addressed, as outlined below:

- Outreach may not be reaching all eligible families
- Materials need to be available in more languages and more widely distributed throughout the State
- It is difficult to cover some health care needs in rural areas, such as high-risk pregnancies or children with special health care needs
- Some families have difficulty understanding and using the health care system
- Some families have trouble with the health care available to them because it is not language or culturally appropriate to their needs

- Some services are not available to all those in need due to provider shortages or inadequate funding.

The Utah Birth Defect Network (BDN) collects data on the prevalence and distribution of pregnancies and births that are affected by a major birth defect. The Birth Defect Network began surveillance activities in 1994 tracking only neural tube defects (NTD). In 1995, oral facial clefts and the common trisomies were included and in 1997, the surveillance was expanded to other birth defects, including cardiac anomalies. In January 1999, the BDN became a full surveillance system collecting all major structural malformations, excluding ventricular septal defects. All potential cases are reviewed by the Director and a pediatric geneticist for classification of isolated versus multiple defects and etiology if known. Demographic data obtained on each case will provide the Bureau of Children with Special Health Care Needs with information about clinic access and distribution by subspecialty. In 2002, the BDN became one of 10 Centers for Birth Defects Research and Prevention in the U.S., making Utah one of the premier locations for research into birth defects causation, as well as into the effectiveness of prevention and intervention.

In addition to needs assessment, the BDN annually evaluates the effectiveness of its folic acid prevention activities on the Neural Tube Defects (NTD) prevalence rates for Utah. These data enable the state to plan for needed health services for families of children with birth defects. The BDN is charged with primary prevention as well as recurrence prevention of NTDs on a statewide basis. Through a small grant from the Utah Chapter of the March of Dimes with matching funds from Baby Your Baby (Medicaid) the BDN Director has trained WIC staff about folic acid preventable NTDs and provided multivitamins with folic acid to all non-pregnant WIC participants from December 2000 to June 2003. In addition, the BDN obtains valuable information from the Behavioral Risk Factor Surveillance Survey (BRFSS), which queries women in their childbearing years about folic acid awareness, knowledge and consumption. The BDN, in conjunction with the Utah Folic Acid Council, utilizes these data to determine prevention activities for the state. Nearly half (48.8%) of all Utah women aged 18-44 reported that they were taking vitamins or supplements with 400 micrograms of folic acid daily. However, folic acid consumption was significantly lower among Pacific Islander and Hispanic/Latina Utah women aged 18-44, and also somewhat lower among those in Utah's Black and American Indian communities. With the Hispanic/Latina community the largest of minorities in Utah, a specific program was developed and utilized during 2003-2004 to target these women in Utah, particularly along the Wasatch Front. Hispanic women within communities were trained to educate other women, currently not pregnant, about the importance of consuming a multivitamin with folic acid daily whether contemplating pregnancy or not.

Local delivery systems

Despite a high number of physicians and mid-level providers working through a variety of private and public agencies, obtaining early, continuous prenatal care remains elusive for Utah women in certain categories. Unmarried teens living at home often do not qualify for Medicaid as their parents' earnings place them over the income standards. Unfortunately, many families caught in this situation either do not have insurance or their carrier does not cover a dependent's pregnancy and they lack adequate cash to cover the teen's pregnancy expenses. Women and their families working at low paying jobs may also find themselves just over income limits, unable to afford insurance, and without sufficient cash for prenatal care. For both of these groups, finding prenatal care in a timely fashion becomes a difficult task.

Another growing segment of the population unable to obtain prenatal services is undocumented women. These women do not qualify for presumptive eligibility and Medicaid is available to them only under the Emergency Medicaid Program for labor and delivery services. One Wasatch Front local health department provides on-site prenatal care through the University of Utah OB Department and enrolls increasing numbers of undocumented, often non-English speaking, women in their prenatal clinics. For these women, paying for needed outpatient and laboratory services is difficult. Community health centers along the Wasatch Front have been faced with the same growing numbers of undocumented women and have had to cap the number of prenatal women they are able to see. In some rural areas of the state, access to prenatal care is difficult for women without a payer as there may be no community health center or providers may not be willing to see them. As a result, some undocumented women are unable to obtain prenatal care and seek medical care only at the time of labor via hospital emergency rooms. AUCH (Association for Utah Community Health, the state's Primary Care Association) is currently engaged in a joint effort with local health departments to assess local needs in order to develop a plan to address the identified needs in each locale.

Easily accessible, affordable family planning services remain problematic for many Utah women. Women on Prenatal Medicaid are only eligible for health care coverage, including family planning, for approximately 2 months following delivery. Following termination of their Medicaid eligibility, many women are unable to afford family planning services. The Primary Care Network, a Utah 1115 Demonstration Waiver project, will enable some women in this category to have coverage for primary care services, including family planning. However, a fifty-dollar enrollment fee, citizenship requirements and limited periods of enrollment are barriers. Work is currently underway by the Division of Health Care Financing (Utah's Medicaid agency) with collaboration and technical assistance by the state Title V agency staff, to submit an 1115 Research and Demonstration for extending family planning benefits for two-years for women who now lose Medicaid eligibility two months after delivery.

Due to funding limitations, local health departments, community health centers and Title X clinics have not been able to meet the demands for women needing family planning services. Most rural local health districts, unable to fund midlevel practitioners to provide family planning services, provide family planning education and subsidize visits to private health care providers for family planning examinations and contraceptive prescriptions. The local health departments may also subsidize purchase of oral contraceptives; however, this service has been significantly reduced due to loss of public health discounted funding by pharmaceutical companies. Many rural areas have no community health center or Title X funded clinics leaving women to navigate private sector providers who are often unwilling/unable to see those who are non-paying. Local boards of health may limit the provision or promotion of emergency contraception. Family planning services are not available in one rural local health district, which does not have a community health center or Tile X clinic. One of four community health centers in the Salt Lake City area has limited family planning services to established patients only. Many teens, at increased risk for unintended pregnancies, are not able to access a Title X clinic (offered through Planned Parenthood Association of Utah, the state's Title X grantee - that does not require parental consent), especially in rural areas. The state law requiring government agencies to obtain parental consent prior to discussing or providing family planning information or services to minors continues to present a barrier to teens needing these services.

The Health and Safety Curriculum for Early Childhood Providers Training, developed under the Healthy Child Care America grant, is currently taught through local partnerships between the

local health departments and Child Care Resource and Referral agencies across the state. The curriculum, available on the Department's website, is a required component for most levels of child care licensure.

In Utah, local providers through contract with the BabyWatch/Early Intervention Program (BWEIP) serve children from birth to 3 years of age. BWEIP contracts with 15 private and public providers throughout Utah to provide direct and care coordination services for these children.

Existing systems and collaborative mechanisms for the three population groups

Preventive and primary care for pregnant women and mothers and infants

The Department of Health toll-free Baby Your Baby Hotline continues to provide information and referrals to callers seeking providers and/or financial assistance for prenatal care, family planning, well child care, nutrition services, or other MCH-related services. The hotline staff collaborates well with community resources in order to promote these and ensure that information is current. The hotline is viewed as a valuable resource for both callers, as well as community resources. The Department sponsors numerous other hotlines that serve the MCH populations. A recent review of Title V Hotlines by the Commonwealth Fund and the Association of Maternal and Child Health Programs highlighted the Baby Your Baby Hotline in an article in press ranking the Hotline as one of the best in the nation.

Each local health department determines which MCH services it will provide based on resources, community priorities and need. Each district receives MCH block grant funds for provision of services for the MCH population, although each varies in which services it offers. Clearly, demand and need for services exceed the system's capacity to provide these services to the maternal and child populations.

Prenatal services, including Presumptive Eligibility (PE) determination, are offered by eleven local health departments (LHDs). One urban LHDs (Salt Lake Valley Health Departments) serves as a site for direct prenatal services that are actually provided by the University of Utah Health Department of Obstetrics and Gynecology. This same health department also serves as a site for children's health care, provided by the University of Utah Department of Pediatrics.

Federal MCH funding has been allocated to two agencies, Salt Lake Valley Health Department and the Community Health Centers, Inc., to support prenatal services to uninsured women. Depending on a woman's payer, all or a portion of the enhanced prenatal services (perinatal care coordination and pre/postnatal home visiting, nutritional counseling, psychosocial counseling and group pre/postnatal education) are available directly or by referral to other agencies.

Eleven local health departments provide presumptive eligibility determination, and all twelve obtain a prenatal history, including obstetrical, nutritional, and brief socioeconomic and psychosocial review. Risk factors are identified and a plan of action developed. The woman is assisted in finding a provider and referrals to other resources are made based on her need. Availability of enhanced prenatal services varies among the health districts and even among an individual health district's sites.

In the past, the system for accessing presumptive eligibility (PE) had been effective; however several years ago problems arose in the Salt Lake County area. Agencies authorized to do PE did not get any reimbursement for the service due to federal regulations. When Medicaid mandated that women along the Wasatch Front enroll in a Managed Care Organization for their prenatal care, PE screening sites changed their policies and no longer screened women for PE determination due to lack of resources. As a result, the PE system, originally designed to promote early access to prenatal care, actually began creating a barrier to care. Women were referred to the

Medicaid eligibility workers to make a direct Medicaid application leaving them without a means of obtaining PE. To remedy this situation, the Division initiated PE by telephone as a pilot project. Women who have private providers in Salt Lake County are scheduled by the Baby Your Baby Hotline for a telephone interview to complete the PE application. The PE card is mailed to eligible pregnant women after completion of the PE process, along with a Medicaid application, Medicaid eligibility worker information, an instruction sheet and referral to WIC. The project, initiated in 2001 has been highly successful. During 2004, almost 2,000 women were screened for PE; almost 75% were issued PE cards to begin prenatal care.

Complete family planning services are only available in seven local health districts, while four provide partial services for women by obtaining medical histories, providing education on contraceptive options, referring women to providers offering discounted services, and providing no or low cost contraception. One health district does not offer any family planning services.

The University of Utah Health Sciences Center has a comprehensive program for pregnant teens in the Salt Lake City area, partially funded by MCH Block Grant monies. This program includes Presumptive Eligibility (PE) screening, prenatal care for the teen and a prolonged period of intensive follow-up for the mothers to prevent rapid repeat pregnancies and well child care for her infant. Four University of Utah Health Centers in Salt Lake City also provide presumptive eligibility for women enrolling in their prenatal programs.

Low cost perinatal and family planning services, utilizing a sliding fee scale, are available in community health centers in the state, including four rural sites. Family planning services based on a sliding fee scale are available through Planned Parenthood Association of Utah (PPAU), the state Title X grantee. PPAU is currently collaborating with the LHDs to provide emergency contraception supplies for qualifying women. MCH has developed a strong relationship with PPAU over the years with much collaboration between the two agencies on a number of common issues.

A clinic for comprehensive health care for homeless individuals is located in Salt Lake City. Presumptive eligibility is available as well as family planning through this agency's contract with Planned Parenthood Association of Utah. A migrant health center in northern Utah, Centro de Buena Salud, in Brigham City, provides presumptive eligibility (PE) screening and antenatal care to eligible women. Prenatal care and family planning services are available to Native American women at Ft. Duchesne in northwestern Utah and at Montezuma Creek and Monument Valley Medical Clinics on the Navajo Indian Reservation in southeastern Utah. Both sites on the Navajo Indian Reservation provide presumptive eligibility screening. Presumptive Eligibility screening is also available through two hospitals located in Salt Lake City.

Maternal and Child Health staff participate with Utah's Department of Health, Division of Health Care Financing, Bureau of Managed Care staff in quality monitoring activities for Medicaid contracted managed care organizations (MCOs). The monitoring activities include periodic site visits to each of the MCOs to access services for pregnant and postpartum women, children with special health care needs and the provision of EPSDT services.

The Utah Department of Health's Division of Health Care Financing (HCF) and Bureau of Maternal and Child Health (MCH) have been working on an expansion of Medicaid coverage for family planning services for women who lose Medicaid eligibility two months after delivery. Prenatal Medicaid income eligibility is 133% of the Federal Poverty Level (FPL). When eligibility ends for these women, they have no coverage for critical reproductive health preventive services. Approximately eighteen states across the U.S. have applied for and received 1115 Waivers in order to extend family planning services for these women. Staff from the two Divisions has been working on coverage benefits and the cost neutrality issues required for submission of 1115 waivers.

The Utah WIC Program has an effective referral process, which is a component of its program for pregnant women and mothers and infants. Current listings and information about other nutritional support and related health agencies are maintained in every WIC clinic and distributed to every participant. Referral agencies on the list include Baby Your Baby, Medicaid, Food Stamp Program, family planning clinics, hospitals, dental clinics, etc. These health-related programs receive outreach materials providing information about the Utah WIC Program and the clinic locations with phone numbers on an annual basis. Local WIC clinics also use routine in-service programs to schedule representatives of other health-related programs to present information that can be used by WIC staff as part of the referral process in working with WIC participants.

The Birth Defect Network, along with WIC, Baby Your Baby, the Utah March of Dimes Chapter, Spina Bifida Clinic at Primary Children's Medical Center, and the University of Utah Health Sciences Center collaborate in the Utah Folic Acid Council to make sure all women of childbearing age and health care providers know about the vitamin's ability to protect against some neural tube birth defects.

The Child Adolescent and School Health Program provides information on SIDS risk reduction through various mechanisms, such as pamphlets, website, educational in-services, and media messages. Due to local health department support for data collection via the home visitation program, the Program has a close working relationship with local health department public nurses. In addition to collaborating with the agencies involved with the Childhood Fatality Review Committee, the Program works closely with the Utah SIDS Alliance, a parent support group, to promote awareness of SIDS grief support and safe sleeping. The Program has provided support to the SIDS Alliance by assisting with the development and mailing of the SIDS Alliance newsletter and event announcements.

Community-based injury prevention programs are available in each of the twelve local health departments through contracts from the Violence and Injury Prevention Program. Community-based injury prevention programs targeting pregnant women, mothers, and infants have included infant and child car seat promotion, occupant protection, water safety, drowning prevention, fire safety, and home safety.

Preventive and primary care for children and youth

Increased efforts to promote Medical Home in new settings for all children came about due to loss of grant funding for the Utah Collaborative Medical Home Project and the planning through the State Early Childhood Comprehensive Systems grant. Methods to educate community service providers on the concept have been explored including providing links to the Project website through other websites. Work with the Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ) is expected to assist pediatric primary care providers in moving toward a Medical Home model through the continuous quality improvement process.

WIC Program clinics throughout the state provide information to parents whose children are WIC participants on other health-related preventive and primary care services for children, including referrals to primary care providers or medical home for well child examinations and immunizations, dental care, and Medicaid and CHIP.

The full-time State Dental Director, who was hired in August 2000, works with other programs in the Department to promote the importance of oral health, such as the Diabetes Program, WIC and Reproductive Health. The Oral Health Program staff work to develop effective strategies to promote oral health in the state and to seek funding for improved oral health among Utah residents.

The Oral Health Program, through a HRSA-funded grant, has provided each of the 12 local health departments with a small amount of funding to develop local plans to promote oral health. Some districts have developed local coalitions formed around the need for improved access for children to dental care, while others have developed specific projects, such as a grade school curriculum on promotion of good oral health. TriCounty Health Department, a rural/frontier district, used the HRSA grant funding to seed a Medicaid-only dental health clinic.

The Oral Health Program has supported fluoridation of community water systems through provision of information and participation in local meetings. The 2000 Utah Legislature passed a bill allowing counties of the second class to present a referendum to its residents to vote on fluoridation. At that time, only two communities in the state (other than military installations and Indian reservations) had added fluoride in their water supply: Brigham City in Box Elder County and Helper in Carbon County. Voters in Davis and Salt Lake Counties approved fluoridation in November 2000; implementation was completed for the most part by October 2003. Legislation to restrict water fluoridation continued to appear in proposed bills in the 2004 and 2005 Legislative Sessions, although they have failed to pass. Davis County held a revote on water fluoridation in November 2004, despite the fact that most communities in the county had implemented the fluoridation of the water systems; residents voted by a narrow margin to continue fluoridating their public water.

Since only one of the local health departments has a dental program to provide for community needs, it is vital for the state to continue to expand its efforts to promote better dental health care and access, especially for disadvantaged populations. The state staff plays a key role in assisting communities, provider and advocacy groups, insurers, and other partners to improve the oral health status of Utah children by developing effective strategies to promote and implement prevention-focused activities and by seeking ways to improve access to oral health care services. The Oral Health Program is committed to promoting oral health as a priority for a broader population of Utahns, i.e., pregnant women whose poor oral health may affect their pregnancy. Additionally, the state needs to continue to advocate for addressing dental needs among MCH populations by developing strategies to improve oral health status.

Using the Oral Health Task Force model implemented in Salt Lake County, an Oral Health Initiative needs to be expanded to include selected communities to build an integrated system of oral health care for underserved children. Collaboration among many players in these communities must be accomplished in order to coordinate growth of the system, outreach and referral, volunteer services, special needs services and public awareness. Prevention must be maximized to reduce the demand upon the system.

The State Dental Director is a member of Utahns for Better Dental Health, a group organized to promote community water fluoridation in Salt Lake County, serves as a consultant to county boards of health throughout the state, which are involved in water fluoridation activities, and also serves as a member of the Utah Dental Association Dental Access Committee. The issue of dental health services for pregnant women and mothers is an area that the Division hopes to expand and to oversee, as well as oral health among other populations.

Activities undertaken by the Salt Lake Valley Health Department Oral Health Task Force, the HRSA grant funded Coordinated Dental Access System and the Health Access Project (HAP) have resulted in increased access to preventive and treatment care among children residing in Salt Lake County. Collaboration among community health center dental clinics, Medicaid dental clinics and school nurses has resulted in a referral system which guarantees children identified with emergency dental needs timely access to care. A similar collaboration among public dental clinics

and volunteers examining Head Start children has resulted in more children being identified in need of dental treatment and accessing care. Children are referred to the appropriate facility based upon the type of treatment required as well as the child's economic/insurance status. Sealant Saturday projects provide occlusal sealants for many uninsured/under insured children. Collaboration among the Oral Health Task Force Prevention subgroup, Utahns for Better Dental Health and the local sections of the Utah Dental Association Utah Oral Health Coalition and the Utah Dental Hygienists Association has made it possible for Salt Lake County residents to vote on community water fluoridation in the November 2000 general election.-Implementation of water fluoridation in Salt Lake County began in October 2003

The Division committed all the Title V federal Abstinence Education Program funds to community-based programs. Eight projects are situated in local health departments, school districts and non-profit agencies. Several projects have expanded their geographic area beyond their home base allowing access to these programs in additional areas of the state. The Division is in the process of reassessing the current projects and plans to issue a new RFP for agencies to apply for funding in fiscal year 2006.

Participation with collaborative groups has provided staff with opportunities to become aware of and have input into some community-based services, including HIV task forces, participation at health fairs, and community teen-pregnancy prevention groups. Head Start-State Collaboration funding provided local early childhood councils with the opportunity to expand their efforts, involve additional partners, and seek local solutions for improving the system of services for the early childhood population. These efforts allow staff to provide technical assistance and support to community solutions to community problems.

Consultation provided to the Child Abuse Prevention Task Force provides an opportunity to share ideas for broad strategies for primary prevention of child abuse including home visiting and parenting education. Community-based injury prevention programs targeting children and youth have included booster seat promotion, child car seat promotion, occupant protection, bicycle safety, bicycle helmet promotion, pedestrian safety, water safety, drowning prevention, falls prevention, fire safety, firearm safety, school safety, and home safety. For the past five years, all LHDs are participating in the implementation of a statewide effort to survey and improve booster seat use among children age 4-8 years.

The major method of coordination between the VIPP and LHDs is through contracts, which allow the program to monitor activities and coordinate with the LHDs. The LHD injury prevention coordinators and the VIPP meet together on a regular basis to discuss problems, successes, and plans for the future. The VIPP actively participates in these discussions and tries to coordinate the various needs and requests. The VIPP has been requiring LHDs to adopt standardized evaluations of the contracted programs. For example, a booster seat project was contracted with all the LHDs and a standardized observation was required so that data could be gathered on booster seat use in Utah.

The VIPP strongly encourages and provides latitude for LHDs to develop and implement intervention strategies that are applicable to local areas. In addition, the LHDs are encouraged to base intervention strategies on current research. Some adaptation to fit the needs of the local area may be necessary and is acceptable; nevertheless the interventions should have a foundation of science. The current Utah Injury Prevention Strategic Plan contains action items under each section that will provide the framework for intervention strategy priorities. A thorough literature review will be conducted to obtain appropriate evidence-based intervention strategies. An annual review of

the VIPP's priorities and contract activities with the LHDs will be conducted to synchronize with the strategic plan.

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Services for children and youth with special health care needs

The CSHCN Bureau provides a number of clinical services for children and youth with special health care needs in the state. Eight clinical programs in addition to the Baby Watch Early Intervention Program provide services to children and families in the state: Birth Defects and Genetics Program; Child Development Clinic; Hearing, Speech, and Vision Services Program; The Neonatal Follow-up Program; School Age and Specialty Services Program; Community-Based Services Program; Fostering Healthy Children Program; and Newborn Screening Program.

Direct services are also provided in the CSHCN Bureau itinerant clinic staffing held with local providers, such as pediatricians, public health or mental health workers, human service workers and families/ family advocates, after the child has been evaluated in the multi-disciplinary CSHCN Bureau clinics, during which a multi-agency care plan is developed for each child. Telehealth is utilized in the itinerant sites, which facilitates ongoing communication between the CSHCN staff, local health department and the schools.

In Utah, children who have SSI are generally eligible for Medicaid, although they must apply for the services. The SSI Specialist in CSHCN works with the Office of Disability Determination Services (DDS) that evaluates disability claims for SSI eligibility. The specialist reviews the claims and provides outreach and referral for appropriate families to Medicaid, which requires a separate application. The specialist also provides information, referral and enabling services to families having difficulty accessing or utilizing services, such as Utah Legal Services, Disability Law Center or consultant staff in DDS. A CHSCN Bureau staff member participates on the DDS Advisory Committee that has fostered cross training of CSHCN Bureau and DDS staff. It also provides the development of professional relationships between SSI, DDS and CSHCN Bureau staff so that conflicts over individual applicants can be resolved. Preschool children who are deaf, blind or otherwise disabled receive early intervention services from Utah School for the Deaf and Blind, Parent Infant Program in collaboration with the Bureau of CSHCN BabyWatch /Early Intervention Program. Rehabilitation services for older children are usually provided by one of three tertiary care facilities, Primary Children's Medical Center, Shriner's Hospital and the University of Utah Health Science Center or private community providers. If the child is SSI eligible, they may access these services through Medicaid in combination with any private health insurance the family may have. CSHCN clinical staff often provides an initial rehabilitation evaluation (especially in rural Utah) and then assists families of these children with information and referral.

Community-based injury prevention programs for youth with special health care needs have included safety restraint use in motor vehicles, bicycle safety, bicycle helmet promotion, pedestrian safety, school safety, fire safety, and home safety.

Preschool children who are deaf, blind or otherwise disabled receive early intervention services from Utah School for the Deaf and Blind, Parent Infant Program in collaboration with the Bureau of CSHCN BabyWatch/Early Intervention program. Rehabilitation services for older children are usually provided by one of three tertiary care facilities, Primary Children's Medical Center, Shriner's Hospital and the University of Utah Health Science Center or private community providers. If the child is SSI eligible, they may access these services through Medicaid in combination with any private health insurance the family may have. CSHCN clinical staff often provides an initial rehabilitation evaluation (especially in rural Utah) and then assists families of these children with information and referral.

State's Effort to Promote Comprehensive Systems of Services

Title V agency has developed strong collaborative relationships with a number of other state agencies, local agencies and private not-for-profit organizations in order to accomplish its work. An example of state agency coordination is the Interagency Coordinating Council (ICC), an interagency group that provides advice to the BabyWatch/Early Intervention Program. The ICC membership represents Utah's statewide early childhood services community and is comprised of 25 members. By specifying types of members included on the ICC, the state is able to bring together clinical staff, political appointees, parents of special needs children, and administrative representatives of various agencies or providers such as Mental Health, Human Services, Education, Department of Insurance, Head Start, Workforce Services, Division of Services for People with Disabilities, physicians and representatives from contract Early Intervention providers. The ICC provides a broad vision of the service system based upon the participation and contributions of all relevant providers and consumers. The mission of the Utah Interagency Coordinating Council (ICC) for infants and toddlers with special needs is to assure that each infant and young child with special needs will have the opportunity to achieve optimal health and development within the context of the family. The ICC has several subcommittees, such as the Parent, Finance, Outcomes, and Transition.

Title V staff work collaboratively with other state agencies, such as the Office of Education, Juvenile Justice, School for the Deaf and Blind, the Office of the Courts, Utah Highway Safety Office, to name a few. These efforts occur in conjunction with various activities to improve the health of mothers, children and children and youth with special needs. The Bureau of CSHCN also works with various state agencies that relate to the population served through its work, such as the Governor's Council on People with Disabilities, Special Education, state vocational rehabilitation, and the Social Security Administration.

<u>Relationship of State and local public health agencies</u>

Representatives of the local health officer association and the local nursing director association are invited to participate in various Division advisory committees or task forces in order to ensure their input and support. MCH programs have staff that work closely with local health department staff on MCH services and needs. The Bureau of Children with Special Health Care Needs contracts with several local health departments to coordinate clinical services for the itinerant clinics in the rural areas of the state. State staff meets with local health officers and nursing directors during their quarterly meetings on an as needed or requested basis.

The relationship between the local health departments (LHDs) and the MCH/CSHCN programs has been strong, although in previous Department administrations it has been strained due to the shift to managed care and tensions over funding. With a new administration, Dr.

Sundwall has made a commitment to working with local health departments. He has also appointed a Department liaison for the local health departments, a position that had been abolished a number of years ago. The local health departments have improved their financial stature by billing for services provided to the public when possible.

Each local health department determines which MCH services it will provide based on resources, community priorities, and need. Each district receives MCH block grant funds for MCH services, although each varies on which services it provides. Eleven of the local health departments provide presumptive eligibility determination.

Staff from MCH Programs provide technical assistance, consultation (administrative and clinical), training and/or mentoring as needed to local health department nurses involved in conducting activities related to maternal and child health services, including prenatal, family planning, nurse home visiting, and school nursing. Program monitoring and data collection are also conducted at the state level to assist in program planning and evaluation. Contracts for MCH services, including immunizations, promote medical home for children. Title V staff has worked with local health department staff to increase awareness of the impact on families when they have to go to more than one place to get care rather than receiving what they need in the same site.

The Oral Health Program works with state and local partners to identify and address oral health needs of Utah's children to assist them in planning, developing, and implementing improved programs and/or effective systems of care and to improve access to and appropriate utilization of dental health services among Utah's children. Consultation and technical assistance services offered by Program staff in regard to needs assessment, statewide data and surveillance, promotion of oral health prevention measures, program planning and systems development, are available to the local health departments as well as to public and private agencies and providers within the State.

Through a HRSA grant, the Oral Health Program has been working with the local health departments to improve oral health awareness. All twelve local health departments were invited to apply for mini grants to improve oral health in their areas. Grants have been awarded to eight of the local health departments with other four receiving funding next year to support oral health activities which will lead to improved oral health of residents living communities statewide

The Bureau of Children with Special Health Care Needs contracts with four local health districts to coordinate clinical services for the itinerant clinics in the rural areas of the state. State staff meets with local health officers and nursing directors during their quarterly meetings on an as needed or requested basis.

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Relationship of State and federally qualified health centers

While the relationship with community health centers in the state is positive and collegial, it needs to be nurtured more since the community health centers are critical for primary care for a large population of individuals without insurance. Division staff has developed a stronger relationship with the State Primary Care Association, State Primary Care Organization and the community health centers by invitations to sit on Division advisory committees, etc.

Three community health centers in Salt Lake County, one in Ogden, Provo, Green River and Bear Lake include dental clinics. The Oral Health Program works with the Association of Utah

Community Health (AUCH), Utah's Primary Care Association, to provide technical assistance to these clinics and encourage the addition of dental clinics in other community health centers.

CSHCN included the Navajo Reservation-based Montezuma Creek Community Health Center in the initial 2001 Utah Medical Home project. One of five practice sites the Family Practice provider and an identified team of nurse and family advocate participated in the three year Medial Home training project. Although the grant has ended, this practice team continues to be an active Medical Home site and they have added four members to their team, including a physician assistant, a medical assistant and an administrator. A second site initially involved in the Medical Home program was the Northwest Community Health Center, a center serving a primarily Hispanic population.

Relationship of State and primary care associations

The Executive Director of the Association of Utah Community Health (AUCH), Utah's Primary Care Association, sits on various advisory committees, such as the MCH/CSHCN Advisory Committee. The Oral Health Program works with the Association of Utah Community Health (AUCH), Utah's Primary Care Association, to provide technical assistance to community health center dental clinics and encourage the addition of dental clinics in other community health centers. The Immunization Program contracts with the State Primary Care Association to promote better immunization rates among populations served by community health centers in the state. The contract relationship has grown over the past five years and is a strong collaborative effort to improve immunization rates for children.

Coordination efforts that address WIC

WIC is located in the Maternal and Child Health Bureau in the Division of Community and Family Health Services. Change in program management and staff over the past several years has resulted in significantly improved coordination with Title V and other programs that serve mothers and children. Collaboration between WIC and MCH programs has been strongly encouraged by the MCH Bureau, Division and Department leadership. The need for collaboration is clearly recognized by the MCH staff and has been strongly supported. WIC State WIC is included as part of a number of Title V activities, such as the MCH Epidemiological workgroup, the MCH/CSHCN Advisory Committee, etc. WIC staff participates in activities and efforts with other programs, such as data integration effort. The Reproductive Health Program collaborates with the WIC Program by providing consultation on such issues as pregnancy intendedness of pregnancy, appropriate weight gain in pregnancy, nutrition during pregnancy, and breastfeeding. The two programs are collaborating on development of education materials related to appropriate weight gain in pregnancy. When possible, PRAMS data are provided to WIC staff to help with their program planning. As a result of these collaborations, Title V programs have been able to enhance the overall continuity and consistency of services provided by all programs.

Within the past two years, the Utah WIC Program and the Immunization Program have developed a stronger collaborative effort to ensure that infants and young children in the WIC Program are screened for DTaP shots and if not up to date, referred to their primary care provider or medical home for follow-up. Modifications were made to the WIC Information System which includes a pop-up box with a message to inform local WIC staff whether the WIC participant is up to date on DTaP immunizations or not. If the child is not up to date, the pop-up box requires local WIC staff to refer the child to his or her primary care provider or medical home. The Immunization

Program purchased age-appropriate books that the local WIC staff gives to the parents as an incentive for having their child up to date on immunizations.

The Oral Health Program has been collaborating with the Utah Oral Health Coalition/Early Childhood Workgroup and WIC in developing educational material for pregnant women and children. A video and pamphlets have been developed for training and education on preventive measures to reduce the incidence of dental disease in the WIC population.

WIC has participated with other programs in the development of an online application process that will include Baby Your Baby, Early Intervention, and other health-related services. This online application process will reduce the time for potential participants to get their applications initiated without having to go into a clinic to make application for services. It will also shorten the administrative time for local clinic staff in processing applications for services.

WIC has committed to adding a half-time data staff member to review and analyze WIC data so that program staff has much improved access to WIC data than previously. WIC staff members participate on various committees related to maternal and child health, including the MCH/CSHCN Advisory Committee, Perinatal Task Force, MCH Epidemiology, immunizations, nutrition, and data integration efforts. WIC nutritionists often serve as resources to other programs serving mothers and children, such as obesity prevention efforts, etc. The collaboration with WIC is much stronger than previously which has resulted in better integration of WIC Program activities with each of the MCH programs and vice versa, working to accomplish the same goal of healthy mothers and children.

While significant progress has been made with the State WIC Program coordinating better and more effectively, the Bureau will continue its efforts on a local level to integrate WIC more fully into the philosophy of the program goals of promoting healthy mothers and children beyond nutrition classes and food vouchers.

Coordination of Title V with Family Planning Programs

Title X dollars are granted to Planned Parenthood Association of Utah with which the Division has a strong working relationship. The Chief Executive Officer of PPAU has actively participated for a number of years on various advisory committees and task forces to address the needs of women of reproductive age in the state. In addition, Planned Parenthood is one of the community grantees of the federal abstinence-only funding to provide "Growing Up Comes First" which incorporates the requirements of the federal abstinence program through maturation classes for elementary youth. The program has standardized maturation classes for schools that utilize it in an environment that previously was an informal, unstructured event that usually involved a speaker (usually a physician parent) talking to 5th-6th graders about "maturation". The "Growing Up Comes First" curriculum addresses issues beyond "maturation", including healthy decision-making, etc.

The Reproductive Health Program provides consultation to 11 local health departments regarding their family planning programs. Education regarding family planning, including emergency contraception, and pre- and interconceptional care has been emphasized and referral to private providers discussed. Local health departments have been supported in their efforts to find funding to sustain their family planning services.

In 2004, the Division of Community and Family Health Services' Maternal Child Health Bureau initiated the Perinatal Task Force to examine issues surrounding perinatal health in Utah, including family planning. A family planning subcommittee, with members from both the public and private provider sector, developed recommendations including support of Health Care

Financing's 1115 waiver to extend Medicaid coverage for family planning services and re-focusing the Baby Your Baby campaign to promote healthy lifestyles prior to pregnancy and in-between pregnancies.

Coordination efforts that address Medicaid /CHIP

The Title V programs in the department have a close working relationship with the Division of Health Care Financing (HCF), Utah's Medicaid agency. Programs in the MCH Bureau as well as those in the CSHCN Bureau regularly work with Medicaid to coordinate efforts for women of childbearing ages and children, including those with special health care needs. The Reproductive Health Program, Child Adolescent and School Health Program and Bureau of Children with Special Health Care Needs staff participate with Medicaid in review of services provided to mothers, infants, children, including those with special health care needs, by the managed care organizations (MCO) or other Medicaid products. This collaboration has provided Title V staff with an opportunity to better understand the MCO systems and other health care systems in the state. This process includes a review of the MCO's quality improvement plan, HEDIS data and other documentation as it relates to services for pregnant and postpartum women, children with special health care needs, and EPSDT services. Medicaid managed care organization contracts include the requirement of a satisfaction survey for special needs populations.

The Reproductive Health Program works closely with colleagues in HCF on a wide variety of projects including: consultative support for oversight of services through their Managed Care contracts, provision of Perinatal Case Management for a sub-group of Salt Lake County Medicaid enrolled pregnant women and collaboration in the administration of the Presumptive Eligibility Program.

The Reproductive Health Program staff work with the Division of Health Care Financing to certify smoking cessation interventions for pregnant Medicaid participants. Medicaid provides some funding for the PRAMS project for the portion of survey participants who are on Medicaid. Medicaid facilitates PRAMS project staff in locating women to participate in the survey through on-line access to its eligibility files. Medicaid also provides program decision support for the PRAMS Project.

Oral Health Program staff has well-established working relationships with Utah's Medicaid staff, and regularly combines efforts with Medicaid staff to improve availability and accessibility of Medicaid dental providers throughout the State. Program staff participated in defining and establishing a basic scope of dental benefits for Utah's Children's Health Insurance Program (CHIP), and continues to serve in a consultative capacity to the Utah CHIP administrator on issues relative to accessing needed dental care for children on CHIP. The Dental Director also consults with the CHIP administrator, the CHIP Advisory Committee and PEHP regarding expanding the CHIP dental benefit package and the PEHP dental provider panel. CHIP enrollment had exceeded projected numbers, resulting in the discontinuation of continuous open enrollment and replacing it with periodic, short duration open enrollments.

The Oral Health Program has been working with Medicaid to promote dental care as a part of prenatal care. Studies have shown an association between periodontal disease and preterm/low birth weight babies. Medicaid's Family Dental Plan clinics, in collaboration with the Oral Health Program, are evaluating this association by undertaking a local study at the Salt Lake and Layton clinics. Pregnant Medicaid women are encouraged to visit the dentist for a dental examination and

thorough teeth cleaning. The data will be analyzed and the results used to promote dental care as an important part of prenatal care to improve the overall health of mother and child.

Title V staff have participated in two grants awarded to Utah Medicaid by The Commonwealth Fund, Assuring Better Child Development (ABCD). ABCD-I supported developmental screenings and targeted case management by public health nurses in local health departments. ABCD-II has built upon the successful implementation of the Early Childhood Targeted Case Management Service developed by the ABCD-I grant. The ABCD-II grant, through UPIQ, has supported social-emotional developmental screening of infants and toddlers by pediatric practices. The third year (2006) of the ABCD- II project will support screening for maternal depression by pediatric practices.

CSHCN Bureau works closely with the Medicaid to insure information for, outreach to and access for potentially Medicaid eligible children and youth with special health care needs and their families. CSHCN houses two on-site Medicaid eligibility workers, who work closely with the Travis C. Waiver Program, CSHCN clinical programs and other Medicaid staff at two adjacent tertiary care facilities. CSHCN staff serves as consultants to the Medicaid Prior Authorization Committee. CSHCN also collaborates in the implementation of several Medicaid pediatric quality improvement grants.

The CSHCN Bureau Director and Therapy Service Coordinator participate in the Medicaid Utilization Review/EPSDT Expanded Services Committee. Through their participation, they have expanded the knowledge base of the Medicaid prior authorization committee to improve the coverage of services to children who are enrolled in Medicaid, resulting in improved coverage of specialty services for children. Of note in the year 2000, the CSHCN Bureau pediatric neurologist and pediatric physical therapist were given voting status on the committee, thus participating in decisions made about expanded care for children. The CSHCN Bureau Director has also participated with the University of Utah Department of Pediatrics to work with the Medicaid Drug Utilization Board, which has helped to improve Medicaid coverage of medications for children.

In the summer of 2004, the Bureau Director of CSHCN was part of a multi-agency, (insurance and managed care organizations) community task force to evaluate all aspects of Medicaid's prior authorization policies and procedures. The summary from this task force documents needed efforts by Medicaid to increase information, coordination, collaboration and efficiency for families, providers, medical homes and insurances around prior authorization issues. In addition, the director continues to participate in the bi-weekly Medicaid Utilization Review and EPSDT Expanded Services Committee. This committee determines coverage of non-covered services for pediatric Medicaid recipients.

The Hearing, Speech and Vision Services (HSVS) Program Manager serves as a consultant to Medicaid. HSVS has collaborated with Medicaid to expand their audiological prosthetic coverage to include digital hearing aids and cochlear implants for children who meet specific criteria.

CHIP in Utah is a stand-alone program administered by the state Medicaid agency. Title V staff from various programs interface with CHIP staff about eligibility, services, and challenges. For example, when Utah CHIP faced a significant budget limitation due to higher than expected demand for enrollment, oral health services were eliminated. The State Dental Director worked with the CHIP staff to quantify the impact of the decision to cut services to maintain the CHIP expenditures within the budget. The CSHCN Bureau continues to work with the CHIP staff to expand services and outreach to children with disabilities or those who are at risk. However, Utah's CHIP program has limited coverage of certain services such as physical, occupational and speech

therapies, mental health, and dental services, so that many of the more severely disabled children find better coverage through SSI and Medicaid. Additionally, as part of all the CSHCN Bureau clinics, resource specialists and/or a Medicaid/CHIP outreach worker provide parents with on-site consultation on accessing resources for coverage of care.

The CSHCN Bureau participated in development of Utah's CHIP program to insure services needed by children with special needs were included. However, CHIP coverage of certain services, such as physical, occupational and speech therapies, mental health, and dental services, is limited so that more severely disabled children referred by CSHCN find better coverage through SSI and Medicaid. CSHCN Bureau continues to work with CHIP staff to expand services and outreach to children with disabilities or those who are at risk. Additionally, as part of all the CSHCN Bureau clinics, resource specialists and/or a Medicaid/CHIP outreach worker provide parents with on-site consultation on accessing resources for coverage of care.

Coordination of Title V with Other federal grant programs

The Division is the recipient of a number of federal grants, including WIC, Immunization Program, PRAMS, Preventive Block Grant, disease-specific prevention grants such as arthritis, cancer, as well as other federal grants, such as Early Hearing Detection and Intervention (EHDI), The Utah Registry of Autism and Developmental Disabilities (URADD), The Utah Genetics Implementation Project (UGIP), HRSA Grant for Coordinated Dental Access System, to name a few.

The Bureau of CSHCN was awarded a CDC-funded grant and has contracted with Utah State University and the University of Utah for Early Hearing Detection and Intervention (EHDI) tracking, research activities, and integration with other newborn screening programs. This is a 5-year grant awarded in 9-30-00 to improve the timeliness and appropriateness of early hearing detection and intervention service to infants and their families by 1) refining and expanding Utah's existing surveillance and tracking for EHDI, and 2) integrating the EHDI surveillance and tracking system with other relevant public health information databases and service systems. Application for continuing CDC EHDI support is currently underway. CSHCN also has funding to support data integration activities and the Newborn Hearing Screening Program through a HRSA EHDI grant.

Efforts are currently ongoing to improve data quality (e.g. accuracy, completeness, timeliness) of the child health information that is used to integrate the health care services provided by UDOH programs, private providers, hospitals, and clinics. CHARM will provide an easy to use, technology based way of providing access to integrated information at the point of service. The CHARM system will act as an electronic broker for participating programs, but it will not replace existing databases.

CSHCN was also awarded a Centers of Disease Control and Prevention grant to establish The Utah Registry of Autism and Developmental Disabilities (URADD). In collaboration with the University of Utah Health Sciences Center and with the Utah Department of education, an epidemiological study is being conducted to determine how many Utah children have Autism Spectrum Disorders and/or Mental Retardation. A key component of the registry is to assist in educating families and services providers about Autism and where to access services.

The Utah Genetics Implementation Project (UGIP) facilitates collaboration with Utah Department of Health (UDOH) programs, community and parent advocacy groups and other stakeholders to develop and implement a shared Birth Record Number among newborn screening programs and birth certificates as well as enable development of educational projects and materials regarding Medical Homes for children with genetic conditions. Additionally, the UGIP assists with

the inclusion of the Newborn Heelstick Screening (NHS) program into the UDOH integrated child health data system, the Child Health Advanced Records Management System (CHARM). The UGIP also makes possible the development of a formal, institutionalized system for adding, changing or replacing screens on the NHS panel.

Coordination of Title V with Providers of services to identify pregnant women and infants who are eligible for Title XIX and to assist them in applying for services

The Division of Community and Family Health Services maintains MOAs with 25 agencies (Qualified Providers) to provide screening for presumptive eligibility (PE) for prenatal Medicaid at 53 sites throughout the state, including 11 local health departments and other agencies such as community health centers, a farm worker health program, a homeless clinic, Indian Health Service provider, University of Utah clinics, several hospitals and a family practice residency program. The Division provides telephone presumptive eligibility screening for Salt Lake County residents through the Reproductive Health Program's Baby Your Baby by Phone.

The Baby Your Baby Hotline refers callers needing financial assistance for prenatal care to their closest Qualified Provider (QP) site. WIC clinics also refer pregnant women needing financial assistance for prenatal care to a Qualified Provider. Women denied PE are referred to either the Department of Workforce Services (DWS) or to one of Medicaid's Bureau of Eligibility Services (BES) outreach workers for a more in-depth screening for Medicaid. QP workers provide presumptively eligible women with Medicaid applications and contact information for their closest DWS or BES office.

The Division collaborates with the Bureau of Health Promotion on media campaigns to promote Baby Your Baby messages. The TV and radio messages in English and Spanish encourage women to call the Baby Your Baby Hotline for information on financial assistance for care. Print materials have been placed in college newspapers, local weekly newspapers along the Wasatch Front and on billboards along major travel routes. Media materials include the Baby Your Baby Hotline number and the Baby Your Baby website address where information on financial assistance for care is available. The implementation of the Universal Eligibility Screening and Application System (UESAS), a web-based online application for programs, such as Presumptive Eligibility, will also increase access to financial assistance for several programs. The UESAS system will accept application for several programs, including Medicaid.

Coordination efforts that address social services

The Division of Community and Family Health Services coordinates its efforts for the MCH/CSHCN populations with many other agencies in the state. The Division of Community and Family Health Services works closely with the Department of Human Services, which serves the maternal and child population statewide related to child welfare, mental health and substance abuse. Title V staff participate on a number of Department of Human Services (Utah's social services agency) advisory committees or initiatives. CSHCN Bureau staff participates on the Health Care Advisory Council for the Division of Child and Family Services (DCFS), Utah's child welfare agency, which meets monthly and advises the DCFS Board on the health status issues for children in their system. The Council identifies barriers and works toward the development of solutions to improve access to and continuity of health care. Another related collaborative effort between the two agencies is the Fostering Healthy Children Program (FHCP). Through this program, CSHCN Bureau nursing staff co-locates with DCFS caseworkers and assists them in coordinating the children's health care. Since all foster children in Utah are covered through Medicaid, the FHCP

staff collaborates closely with Medicaid to ensure that services are accessible for this population of children with special needs.

Within the Department of Human Services, the Division of Mental Health and the Division of Substance Abuse were combined in 2002 into a single entity, the Division of Substance Abuse and Mental Health. Department of Health staff has sought to strengthen the relationship with the Division of Substance Abuse and Mental Health by establishing regular meetings in which the two agencies discuss issues and opportunities for collaboration.

The Department of Human Services, Division of Substance Abuse and Mental Health was awarded a five-year grant to develop infrastructure for mental health services for children and adolescents in the state. The Title V Director serves on the Steering Committee for this grant (UT CAN – Utah Children and Adolescent Network) and other Title V staff members are participating on the practice workgroup of UT CAN. One of the challenges will be to increase awareness about the role of the pediatric primary care provider in addressing mental health issues in children and adolescents.

Title V staff participates on the Child Abuse and Neglect Council, through the Division of Child and Family Services (DCFS). The Council brings parent representatives and over twenty organizations together to address child abuse prevention and treatment issues and provide input on the management of the Children's Trust Fund. The Prevention subcommittee, with representatives from the Utah Department of Health's Fostering Health Children and the Child Adolescent and School Health Program, develops and distributes outreach materials as well as provides recommendations to the DCFS Board on prevention issues. The Legislative subcommittee monitors and provides comments on legislation affecting abused and neglected children. The Council supported the recommendations of the 88-member Utah Child Abuse Prevention Task Force for providing primary prevention strategies, through the Children's Trust Fund, to promote safe and healthy families.

Mental health services are available privately and through Medicaid Prepaid Mental Health Plans throughout Utah. However, services are frequently not adequate for children, especially those who are under five years, living in rural Utah, dually diagnosed with mental health and chronic illness, or served by numerous agencies. A collaborative effort involving multiple agencies, including the CSHCN Bureau, is underway to improve the mental health services for children in the state. In 2004, the Department of Human Services, Division of Substance Abuse and Mental Health received a grant to collaborate in improving the Mental Health Service System infrastructure throughout Utah called Utah's Transformation of Child and Adolescent Network (Utah CAN). The Bureau of CSHCN is collaborating with this effort especially through its Medical Home initiatives, including the MedHome Portal website

CSHCN Bureau staff participates on the Health Care Consortium Council for the Division of Child and Family Services (DCFS), Utah's child welfare agency, which advises the DCFS Board on health issues for children in their system. The Council identifies barriers and works toward solutions to improve access and continuity of health care. Through the Fostering Healthy Children Program (FHCP), CSHCN Bureau nurses co-locate with DCFS caseworkers and assist them in coordinating the children's health care. Since all foster children in Utah are covered through Medicaid, the FHCP staff collaborates closely with Medicaid to ensure that services are accessible for this population of children with special needs.

The Baby Watch/Early Intervention Program is collaborating with the Department of Human Services, Division of Child and Family Services (DCFS) to develop policy and procedures for the referral requirements under the Child Abuse Prevention Treatment Act (CAPTA). The new

law requires the referral of children with substantiated cases of abuse and neglect to the Baby Watch program. The policy will include new DCFS procedures for child protective personnel to utilize a developmental screener for children birth to three at their initial home visit. Children who show potential problems will be referred to the BWEI program. Local BWEI service agencies will partner with local DCFS personnel to train on the developmental screener and to design procedures for referral of children suspected of having a developmental delay. BWEI and DCFS have received a $10,000 grant from the National Association of State Directors of Special Education to support this work.

Coordination of Title V with Family Leadership and Support Programs

CSHCN has hired the Utah Family Voices Director to provide consultation and support to CSHCN programs and families, as well as to infuse and enhance family centered values into all CSHCN Bureau programs and initiatives. The Family Voices Director works closely with the Utah Parent and Information Center in teaching and mentoring other families of children and youth with special health care needs. CSHCN also contracts with the Liaison for Individuals Needing Coordinated Services (LINCS) to provide direct services.

Coordination efforts that address school health

School health in Utah is addressed in several ways. The state Title V agency houses the Child Adolescent and School Health Program, which addresses to a minimal degree school health needs. In addition, the School Nurse Consultant, housed in the Immunization Program, works with school nurses in the state on school nurse issues, such as delegation and appropriate policies for school nursing roles. Utah's high ratio of students to school nurse makes the role of the school nurse very challenging. The issue of school health will require further discussion and development of strategies to improve the Department's involvement in school health. Unfortunately the State Office of Education does not have a staff member responsible of school health, making coordination with the State Office on this issue very difficult.

In Utah, children from birth to 3 years of age are served by local providers through contract with the BabyWatch/Early Intervention Program (BWEIP) located in the Bureau of CSHCN. Children 3-5 years of age receive early intervention services through the local school districts. Because of the strategic positioning of the Birth-3 BWEIP, CSHCN Bureau staff has a close working relationship with the state level staff and the contracted local service providers. The CSHCN Bureau Director hosts the Interagency Coordinating Council for the BabyWatch Early Intervention Program. The membership of this Council ensures a forum of collaboration among all the organizations and agencies and families of all preschool children in early intervention programs including MCH staff; State Office of Education; Services for Persons with Disabilities; School for the Deaf and Blind; Mental Health; Utah State University; State Office of Child Care, early intervention providers, parents; and a legislative representative.

Coordination efforts that address special education

CSHCN Bureau and the Office of Students at Risk (SARS), Utah's state level special education program, enjoy a strong working relationship and have collaborated on a number of projects. For instance, CSHCN Bureau participated in the Office of Special Education's 5-year strategic planning process. In 2005 a staff member from SARS was added to the MCH Advisory Committee for the subcommittee for children with special needs. CSHCN Bureau and SARS are

working together through the Utah Registry of Autism and Developmental Disabilities (URADD) grant to identify children with autism.

Coordination efforts that address early intervention

The BabyWatch Early Intervention Program (BWEIP) in the state Title V agency has fostered the facilitation of services and referrals between the programs, the provision of joint training and the coordination on contract development. BWEIP staff collaborates with other programs outside the Department, such as working with the Department of Workforce Services Office of Child Care to design a system of subsidized childcare payment for children with disabilities. For these children, the reimbursement rate to childcare providers is enhanced, dependent on the family income. BabyWatch Early Intervention Program (BWEIP) has also developed formal agreements between local Early Head Start and local Early Intervention programs for improved service delivery maximizing the resources of both agencies. Due to these agreements, BWEI programs may provide early intervention services to a qualified child in the Early Head Start setting. Another example of linking is the InReach Project in which Utah State University, BWEIP and the University of Utah Medical Center are collaborating to allow families to be contacted by early intervention professionals before their child leaves the newborn intensive care unit. When the family and the BWEIP staff make contact, services are offered and an Individualized Family Service Plan (IFSP) is developed in anticipation of the infant's arrival home.

The Baby Watch/Early Intervention Program is designing and implementing a state database called Baby & Toddler Online Tracking System (BTOTS). The first phase of BTOTS, which has been implemented, provides the capability to move specified data from the Early Intervention provider locations to the state BWEI Program database. Phase Two of BTOTS, will provide the capability for the local early intervention provider to perform their core, day-to-day activities and services as well as provide comprehensive data on the children and families they serve. The state BWEI Program will be able to access the data from all providers in the state and to produce reports on various aspects of the program. This function will significantly enhance federal requirements for data and compliance with IDEA regulations, but more importantly will provide data for quality improvement measures.

CSHCN Bureau staff has been active in providing technical assistance and consultation for a number of community development efforts. The BWEI program has a credentialing program for all early intervention staff. The credential requirements include in-service training in order to increase the skills of persons delivering services to children and families.

Coordination efforts that address developmental disabilities

CSHCN Bureau works with the Division of Services for People with Disabilities (DSPD) in a number of ways. Representatives from DSPD are on the BabyWatch/Early Intervention Program (BWEIP) Interagency Coordinating Council. The Division of Community and Family Health Services, which houses the CSHCN Bureau, is involved with the Coordinating Council for People with Disabilities, which includes participants from Medicaid, vocational rehabilitation, special education, and mental health to review difficult issues, coordinates interagency treatment funding for individuals.

Coordination efforts that address SSI and State Disabilities Determination Services Unit

In Utah, children who have SSI are generally eligible for Medicaid, although they must apply for the services. The SSI Specialist in CSHCN works with the Office of Disability

Determination Services (DDS) that evaluates disability claims for SSI eligibility. The specialist reviews the claims and provides outreach and referral for appropriate families to Medicaid, which requires a separate application. The specialist also provides information, referral and enabling services to families having difficulty accessing or utilizing services, such as Utah Legal Services, Disability Law Center or consultant staff in DDS. The SSI Specialist also participates on the Disability Determination Services Advisory Committee that has fostered cross training of CSHCN Bureau and DDS staff. It also provides the development of professional relationships among SSI, DDS and CSHCN Bureau staff so that conflicts over individual applications can be resolved.

Coordination efforts that address vocational rehabilitation

In Utah, the Office of Vocational Rehabilitation (VR) is housed in the State Office of Education. CSHCN Bureau staff participates on a number of working and advisory committees to the vocational rehabilitation programs and the two programs have recently developed an interagency agreement. The Program Manager for Hearing, Speech and Vision Services is a past-chair of the Vocational Rehabilitation Advisory Council, spent six years on the Advisory Council, and continues to collaborate with Vocation Rehabilitation on other projects.

CSHCN staff members are active in the Utah Center for Assistive Technology Center (UCAT), part of the Office of Vocational Rehabilitation, through coordinating direct care for individuals with disabilities, advisory boards, contractual assistive technology services and support of the UCAT assistive technology helpline and website, "Access Utah". CSHCN provides a staff member to the Traumatic Brain Injury Advisory Committee, which is housed in the state Vocational Rehabilitation office. This Council is currently working on a statewide TBI Implementation Project to improve services and supports to individuals with traumatic brain injury and their families. A member of Voc Rehab sits on the CSHCN Medical Home Advisory Council. The MedHome Portal Website has worked with Vocational Rehabilitation office advisors to develop the transition to adulthood module on the website.

Coordination efforts that address state interagency transition programs

CSHCN Bureau has established a Systems Development Program which houses the Bureau's transition to adulthood efforts. In addition to establishing the full-time SSI Specialist/Program Manager, the CSHCN Bureau has contracted with a specialist to provide transition services, such as vocational/career, health and financial planning, to young adults (14 years of age and older). This specialist provides transition training and consultation to CSHCN Bureau staff, other agencies and health professionals and assists individuals and their families in developing and implementing individual transition plans.

Coordination efforts that address SSDI

The SSDI grant in Utah is supporting the CHARM data linkage efforts as mentioned previously. The SSDI Coordinator is housed in the Bureau of Children with Special Health Care Needs. The CHARM Project is supervised by the state Title V Director.

Coordination efforts that address Ryan White

The HIV/AIDS Program in the Department of Health, Division of Epidemiology and Laboratory Services administers the state's Ryan White Program. Utah does not have a Title IV grant due to its inability to compete because of its low rates of women, infants and children infected with HIV. Utah's Ryan White Program is required to spend approximately 10% of its

funds, or $303,000, on direct and support services to women, infants and children. This funding supports services such as health insurance continuation payment, purchase of High Risk Insurance Pool (HIP) coverage, drug assistance, childcare, transportation and case management services. The Division of Community and Family Health Services participates on a committee with staff from the Division of Epidemiology and Lab Services and pertinent community partners to coordinate state level services to women, infants and children with HIV/AIDS and to improve prevention efforts related to transmission of perinatal HIV. Membership of this collaboration committee includes staff from the Department's Reproductive Health Program, Medicaid, Baby Your Baby and WIC. CSHCN Bureau has had few referrals of children to the Technology Dependent Waiver Program, although most of these children receive medical coverage through Medicaid and Ryan White funds.

Relationship of State and available technical resources such as public health and health professional educational programs and universities

There are two schools of public health in Utah, both offering Master of Public Health degrees and one offering a PhD in Public Health. Department of Health staff members have participated in teaching classes on Introduction to MCH Public Health, serving as mentors to students in these programs, as well as other disciplines, such as health education, nursing, etc. Faculty members from academic programs are invited to participate in various Title V activities. The University of Utah's Department of Family and Preventive Medicine and the Department of Obstetrics and Gynecology collaborate with MCH staff on a perinatal epidemiology group sponsored by the University. Staff from these departments, as well as the College of Nursing, participate in the review of fetal, infant, and maternal deaths in the state. Members of these groups are regularly available for technical and clinical questions.

The University of Utah has been working on a proposal to build a dental school, which to this point has not been particularly well received by the dental community.

The Oral Health Program participated in the National Governor's Association oral health policy institute. The Program is working with Medicaid to submit an application for the Purchasing Institute sponsored by the Center for Health Care Strategies, and is also working with Regional HRSA staff to develop a regional effort to promote oral health.

The Utah Department of Health collaborated with the Nevada State Health Department to develop the Great Basin Public Health Leadership Institute, (GBPHLI) which graduated its first class in March 2005. The GBPHLI is now housed at HealthInsight, the state PRO. The second class will begin in May 2005 and will include Department staff familiar with Title V. The leadership capacity in the Department will be enhanced as more Department staff graduate from the Institute.

Utah CSHCN is in its third year of the MCHB funded Utah Leadership Education in Neurodevelopmental Disabilities (ULEND) program. Through ULEND, CSHCN is collaborating with Utah State University, Center for Persons with Disabilities and University of Utah, Department of Pediatrics, School of Medicine, in an MCHB Leadership Grant. ULEND provides opportunities for students and professionals from a variety of health related disciplines (e.g. pediatrics, physical and occupational therapy, speech-language pathology, psychology, nutrition, social work, audiology, pediatric dentistry, genetics, nursing, business/marketing, special education, and families) to increase their knowledge and skills in providing services and supports to children with neurodevelopmental disabilities. With the growing trend towards collaborative interdisciplinary efforts in the health care field, there is a demand for persons with enhanced teamwork skills who have had experience working with individuals from a variety of disciplines to provide services to children with disabilities.

CSHCN staff is involved with a number of different colleges and Universities in providing internships for health profession students, such as nursing, pharmacy, pediatric residents and fellows, social workers and health educators. The Medical Home project has employed the services of these health profession students for different types of project development

The Oral Health Program has worked with the Division of Professional Licensing (DOPL) to promote public dental health agendas. The dental hygiene and dental assistants associations have been especially helpful in support of dental sealant projects. The State Dental Director has worked hard to establish a strong collaborative relationship with the Utah Dental Association and has been very successful in engaging their leadership in oral health promotion and advocacy activities. Collaboration with the University of Utah Dental Education Program has been very beneficial in increasing dental access to a vulnerable population through their residency program.

Coordination efforts with major providers of health and health related services, such as children's hospitals and tertiary medical centers, AAP, ACOG, AAFP, family and parent advocacy organizations

The Division works closely with the tertiary care facilities. The five tertiary perinatal centers in the state are the University of Utah, St. Mark's Hospital and three hospitals owned by the Intermountain Health Care (IHC) system. Perinatologists and neonatologists in the tertiary centers are faculty members at the University of Utah making for a strong collaborative model of tertiary care in the state. The University of Utah Health Sciences Center is a tertiary care center for perinatal care and faculty from the University are involved in a number of Department efforts to improve health of mothers and children. Faculty sits on several advisory committees, task forces, etc. and Department staff sits on some of their committees as well.

Division staff has strong relationships with IHC staff and has worked with IHC, University of Utah, and representatives from other health systems to update and disseminate a report on Cesarean sections to include a different classification analysis, vaginal births after Cesareans, and morbidity outcomes associated with rates and rate changes.

Utah is fortunate to have Primary Children's Medical Center (PCMC), which is one of the Regional Centers of Excellence of Care for Children from several states, including Utah, Idaho, Nevada, Wyoming, and Montana. This Center, combined with the Shriners Hospital for Children, provides state-of the-art acute, chronic and tertiary care for children with special health care needs and their families. The Oral Health Program has an ongoing relationship with Primary Children's Medical Center. Their participation in statewide oral health activities has been invaluable in providing prevention education and treatment care.

CSHCN Bureau has an excellent working relationship with these centers, and works closely with their staff through a number of ongoing advisory committees, such as the American Professional Society on the Abuse of Children, the American Academy of Pediatrics/Intermountain Pediatric Society Pediatric Continuing Education Committee, and the MCH/Medicaid sponsored Managed Care Task Force which was developed to improve the quality of care provided for Utah children with special needs.

CSHCN Bureau has collaborated with Shriners Hospital for Children in the Intermountain Collaborative Transition Center project, initiated by an MCH/SPRANS grant, "CHOICES." Through this project, CSHCN Bureau staff participates in an interagency advisory committee and collaborates in large and small group training workshops.

The Utah Collaborative Medical Home Project is a collaborative effort with the University of Utah Department of Pediatrics, Utah State University, Medicaid and Utah Family Voices that

provides outreach and support to medical homes statewide for children with special health care needs (CSHCN) in primary care settings. Originally funded by an MCHB grant, the project continues to expand throughout the state and is guided by a broad based advisory committee, composed of private pediatric and family practice physicians, families, allied health professionals and other state partners, such as Education, Vocational Rehabilitation and Medicaid. The strategic plan for children and youth with special health care needs for Primary Children's Medical Center (PCMC) includes an action step to support Medical Homes. The CSHCN Director serves on the PCMC Pediatric Education Services Continuing Medical Education committee. This is the credential committee for CME credits for physicians and it identifies the topics to be presented in Pediatric Grand Rounds statewide. The CSHCN Director is also involved in University of Utah and PCMC based health services research committee. The CSHCN Family Advocate Coordinator serves on the Family Advisory Committee for PCMC.

University of Utah Department of Pediatrics' physicians serve on numerous CSHCN advisory committees, including the BWEIP Interagency Coordinating Council, the Medical Home Advisory Council, the Newborn Hearing Screening Advisory Committee and the Genetics Advisory Committee.

The Division has effective relationships with the tertiary facilities in the state. Primary Childrens Medical Center (PCMC), one of two children's hospitals in the state, works closely with the Bureau of Children and Youth with Special Health Care Needs to coordinate services for children with special needs. PCMC physicians participate in the Department of Health's Child Fatality Review Committee that reviews deaths of all children that are possibly considered preventable, such as those due to suicide, child abuse or neglect, drowning, motor vehicle crashes, etc.

MCH staff involves faculty from the University of Utah Health Sciences Center Departments of Family and Preventive Medicine, Pediatrics, and Obstetrics and Gynecology, and the College of Nursing on a number of projects, such the state's Perinatal Mortality Review Program. The University of Utah is one of several tertiary medical centers in the state for perinatal care. Faculty members from each area mentioned above participate on the review committee and actively participate in the review process including review of records, determination of preventability and recommendations to prevent future deaths. Data and recommendations from the review process have been presented by University faculty at various meetings, such as the American Academy of Pediatrics, and have been published in a peer review journal. Coordination of the review process with University faculty has ensured the success of the perinatal review program's work.

University of Utah Health Sciences Center faculty invite Title V staff to work on University programs, projects and initiatives, such as the Masters in Public Health Program (Introduction to MCH Public Health course), and Perinatal Epidemiology workgroup. The state MCH epidemiologist is providing data support to a NIH grant funded project that the University of Utah is conducting related to fetal death.

The Perinatal Task Force, sponsored by the Title V agency, includes representatives from the Utah Chapter of the Association of Certified Nurse Midwives, the Utah Chapter of the American Association of Family Physicians, the University Health Sciences Center, the Salt Lake Valley Health Department, Intermountain Health Care, the Association of Women's Health Obstetrical and Neonatal Nurses and others on a new effort to transform data to action, the Perinatal Task Force. The task force was put together with the goal of turning data into action around priority perinatal issues. The Task Force prioritized four issues that subcommittees are working on this year:

postpartum depression, prenatal care, preconceptional/family planning, and prematurity. The goal is for the subcommittees to recommend achievable strategies to address their respective issues.

Title V staff work with Intermountain Health Care (IHC), the largest health care system in the state, to improve perinatal and neonatal care in the state. Department staff works with providers in these centers on a number of initiatives, including appropriate site for delivery of low birth weight infants, Perinatal Task Force, electronic medical records, etc. Because of ongoing relationships and identification of issues related to perinatal care based on vital records data, such as the state's high induction rates (higher than national averages), IHC instituted a system-wide policy outlining the criteria for elective inductions. Discussions about the declining percentages of very low birth weight births occurring outside tertiary centers led to a policy change which set the criteria for gestational ages for hospitals in their system. Since almost half of the delivering hospitals in the state are part of the IHC system, changes in policy in response to data concerning provider practices have a large impact on the health care system in the state overall.

The Oral Health Program coordinates with the Utah Dental Association Dental Access Committee and the Utah Dental Hygienists Association in securing and training volunteers for various activities including Sealant Saturdays and Head Start dental examinations. The State Dental Director serves as a consultant to and coordinates activities with the director of the dental clinics in two community health centers in Salt Lake County.

The chair of the state ACOG chapter and members of the Intermountain Pediatric Society and the Utah Family Practice Physician Association participate on the PRAMS Advisory Committee, which provides an opportunity for input to perinatal issues and to strengthen the relationship between the Department of Health and these local professional association chapters. Division staff arranged with ACOG to donate more than 250 packets entitled "Routine Prenatal HIV Screening" that CFHS, in collaboration with Health Care Financing and HIV/AIDS, mailed to 200 family practice and CNMs performing deliveries in the state. In addition, the Reproductive Health Program has distributed these packets to local health departments and Baby Your Baby sites throughout the state.

Through the Utah Pediatric Partnership to Improve Healthcare Quality, the Division is expanding its role in providing technical assistance and support directly to primary care providers in partnership with the Utah Chapter of the American Academy of Pediatrics, the Intermountain Pediatric Society.

Division staff has collaborated with other professional organizations, such as HealthInsight, Utah's Peer Review Organization, as well as several other partners to educate prenatal and pediatric providers on the "5 As" developed by the U.S. Public Health Service as a standard of care of smoking cessation intervention. Division staff has also worked with the Utah Chapter Chair of ACOG on the concern that obstetrical providers are challenged with increasing malpractice insurance costs with unchanging reimbursement rates for prenatal and labor and delivery care. The concern is that providers in the state may be choosing to limit or drop obstetrical care due to increasing overhead costs without accompanying increases in reimbursement.

The Birth Defect Network has a close relationship, in fact, a partnership, with health care professionals at the University of Utah Health Sciences Center. A pediatric geneticist and medical ethicist in the Department of Pediatrics are actively involved with the BDN in both a supportive and advisory role. It is anticipated that this relationship will be strengthened even further with the reconstitution of the Genetics Advisory Council through activities of the Genetics grant recently awarded to the Department by the federal Maternal and Child Health Bureau Genetic Services Branch. The activities to be pursued with funds from the grant are: 1) assessment of needs for

statewide genetic services; 2) development of a state genetics services plan based on that assessment; 3) assessment of needs for child health data integration; and, 4) development of a plan for implementing coordination and integration of the data. Initial emphasis will be placed on planning for the integration of vital records, birth defects and immunization registries and newborn hearing and newborn heelstick screening data.

WIC staff has improved coordination efforts to provide quality nutrition care by consulting with private health care providers and local hospitals including Primary Childrens Medical Center. This consultation effort with health care providers is especially critical for WIC participants who are designated as high risk and have been prescribed a specialty formula for such medical conditions as inborn errors of metabolism, failure to thrive or prematurity. In addition, WIC staff share information related to policies, procedures and recommendations with the Utah Chapter of AAP through articles and references published in the organization's newsletters.

CSHCN has collaborated with the American Academy of Pediatrics on the initial development of the Utah Medical Home Initiative, including "Every Child Deserves a Medical Home" training, development of the MedHome Portal website and networking with other states' medical home projects. Locally, the Bureau has collaborated extensively with Utah Chapter of the American Academy of Pediatrics, the Intermountain Pediatric Society (IPS), on medical home projects including an initial physician survey of needs regarding capacity to provide a robust Medical Home. Dr. Chuck Norlin, the current President of IPS, and CSHCN Bureau Director met with the President of the Utah Chapter of American Academy of Family Practice to discuss the definition and potential collaborative efforts regarding medical home. The CSHCN Director is an active member in the AAP Committee on State Government Affairs (COSGA) and chairs the AAP Newborn Hearing Screening task force.

The CSHCN Bureau participates in the Intermountain Pediatric Society Children with Special Health Care Needs Committee, which includes CSHCN Bureau staff, academic pediatricians from the University of Utah Medical Center and private pediatricians from one urban and one rural area. This committee helped to develop the initial CSHCN resource guide for primary care providers statewide. In collaboration with members of this committee, CSHCN Bureau staff has developed a number of modules for the MedHome Portal website on issues for CSHCN and their families. Topics thus far have included medical necessity, medical home, collaboration and resources for "medically challenged" children, and discharge planning from an acute care facility.

The CSHCN Bureau collaborates with representatives from the major parent advocacy organizations, including the Utah Parent Center, Utah Family Voices, LINCS and the Legislative Coalition for People with Disabilities to support bureau strategic planning and to review and develop policies. The Bureau also contracts with staff from each of the following parent advocacy organizations: Utah Parent Center; Family Voices; LINCS; and Allies for Children to consult in the development of care plans for children with special needs.

<u>Development and implementation of standards of care, guidelines, monitoring of program effectiveness, and approaches to the evaluation of care, including efforts to monitor continuous quality improvement for each MCH population group</u>

Maternal and child health staff, representing the three populations served through Title V funding participate with the Division of Health Care Financing (DHCF) staff in quality monitoring activities of the managed care organizations (MCO) contracting with the state to provide services to women and children enrolled in Medicaid along the Wasatch Front. Professional nursing staff from the CFHS Bureaus of Maternal and Child Health (Child Adolescent and School Health Program and

Reproductive Health Program) and Children with Special Health Care Needs (Community Based Services Program) collaborates with HCF staff in conducting quality reviews and on-site visits to the MCOs. The monitoring includes periodic site visits to review prepared written documentation, such as health plan policies, manuals, and education materials as well as staff interviews to assess compliance with established standards for MCH population health care. Standards are used to assess a variety of areas including identification and provision of services for pregnant and postpartum women, and EPSDT/CHEC services for children including those with special health care needs. The site reviews are an opportunity for Title V staff to provide information and updates on new areas to focus, such as interpregnancy spacing, immunizations, public health programs and educational offerings available for plan recipients as well as educational opportunities for MCO staff. Additionally, CSHCN Bureau staff continues to work with Medicaid and Medicaid MCOs to improve care to children with special needs through the MCH/Medicaid sponsored Managed Care Task Force, developed to improve the quality of care provided to Utah children with special health care needs. A report of findings of the site visit on compliance with the standards including recommendations is developed with input and recommendations from all three MCH areas.

After the initial review, each MCO is re-evaluated every 1-2 years to follow up on previous recommendations and findings. Standards that were found unmet are reassessed and further recommendations are made, if needed. CFHS consultants continue to be involved in collaborative efforts with HCF colleagues to streamline and improve the effectiveness of the Medicaid MCO quality monitoring standards and process. The consultants have strengthened their role in providing technical assistance and direct consultation to both the MCOs and the HCF managed care staff with updates, policies and standards related to MCH populations.

Since the University of Utah Department of Obstetrics and Gynecology has faculty assigned to each of the five perinatal tertiary centers in the state (three of these are IHC facilities), the MCH Bureau and its program collaboration on reproductive health issues yields a broad stroke of impact on perinatal services in the state, promoting improved care and practice standards.

The PRAMS project data provide a mechanism for monitoring quality of care because it queries women about provider practices regarding counseling on a variety of topics during their prenatal care, such as HIV testing, drug and alcohol use. These data assist the program in targeting issues for continued provider education.

The Reproductive Health Program has worked closely with internal and external partners to promote Centers for Disease Control and Prevention/ACOG Guidelines for the prevention of transmission of Perinatal HIV. Statewide mailings of revised guidelines to prenatal care providers throughout the state have been accomplished. Surveillance of prenatal care provider practice related to testing and counseling for HIV has also been accomplished. The Utah PRAMS survey has been revised to better capture evaluation of this important prenatal screening practice. Statewide mailings to prenatal care providers have been utilized to distribute information on screening for postpartum depression. Both prenatal care providers and pediatricians received information on screening for substance abuse during pregnancy. Labor delivery units around the state were provided with the CDC's revised screening guidelines and algorithms on prevention of perinatal Group B Streptococcus disease. Information on provision of interpreters and emergency contraception was provided to prenatal and family planning public health nurses in local health districts.

The Reproductive Health Program worked with the Department's Bureau of Licensing to amend rule 432-100-17 of the Utah Administrative Code by incorporating the recommendations from the American Academy of Pediatrics' and the American College of Obstetricians and

Gynecologists' *Guidelines for Perinatal Care (5th edition).* The previous rule did not include standards for labor and delivery for hospitals. It is hoped that adoption of these standards in the amended rule will reverse the trend of VLBW infants being born outside of facilities designated for high-risk delivery and neonates.

The Utah WIC Program has compiled national and state policies into a very clear concise Policy and Procedure Manual, which is distributed to local WIC agencies each year with changes highlighted. Many quality improvement committees are jointly attended by state and local WIC staff including nutrition education, breastfeeding, computer issues, and risk factors. Numerous training manuals with progress checks and evaluations have been developed to assist all WIC agencies in maintaining staff competencies for ensuring delivering of quality nutrition services. Standards of care and guideline are updated by providing employee in-service programs which are nationally recognized and / or accredited.

The Utah WIC Program conducts a periodic survey of its participants to determine their satisfaction with provided services, classes, etc. The survey information is used to determine needed changes in program approaches to better serve participants.

Each local WIC agency is monitored every other year and evaluated for compliance with federal regulations and state policy. Each local agency develops an annual Nutrition Education Evaluation Plan, which is submitted to the State WIC Program for approval. The evaluation process includes a detailed needs assessment including demographic and health data. During this process, clinic staff compares progress made toward meeting the Healthy People 2010 Goal and Objectives. Each agency chooses three target areas to work on and develops appropriate goals for the upcoming year. In addition local agencies conduct periodic quality assurance audit to measure performance objectives in their clinics.

Beginning in 1999 the Newborn Screening brochure has included information on the Utah Birth Defect Network (UBDN). The Newborn Screening Program continues to distribute this brochure to all delivery hospitals. Each delivery hospital is asked to give the brochure to every mother who delivers a baby at the facility. The information on UBDN includes general information about birth defects and provides a toll free UBDN number for questions or information. As questions arise regarding birth defects, information is gathered from existing anticipatory guidance as well as other medical literature and compiled for families. The compiled information along with physician referrals and any other requested information is mailed directly to the individual. A logbook is maintained for all calls with requests for information.

Dental decay in children is largely a preventable disease, yet it is the number one chronic childhood disease. The American Dental Association and the American Academy of Dentistry for Children recommend for dental visit by one year of age. In a 2002 survey conducted by the Oral Health Program, only 16% of dentists in Utah indicated they see children at one year of age. The Oral Health Program has been actively promoting first visit by one by developing educational pamphlets, preparing articles for dental professional newsletters and encouraging the Utah Dental Association to educate their membership on this important recommendation.

The Division has collaborated with Medicaid on a Commonwealth Fund/National Academy of State Health Policy project focused on building capacity of Medicaid programs to support effective child health and development services for Medicaid enrolled children under age five. The Assuring Better Child Development (ABCD) I grant allowed Medicaid to begin the Early Childhood Targeted Case Management Services to provide case management for children from birth to age four. Division staff is currently collaborating with Medicaid on another Commonwealth Fund/National Academy of State Health Policy project, the ABCD II grant, to promote screening

for mental health issues among young children and their mothers. This collaborative with Medicaid resulted in increased social-emotional and developmental screenings of infants by pediatricians through the Utah Pediatric Partnership to Improve Healthcare Quality. The second year of the project has focused on social-emotional screening for toddlers while the third year of the project will focus on screening for maternal depression.

The Intermountain Pediatric Society/Utah Chapter, American Academy of Pediatrics (IPS), which established the Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ), is addressing quality improvement issues for pediatric care in Utah. UPIQ is modeled after the Vermont Child Health Improvement Project (VCHIP) and receives ongoing guidance from leaders of VCHIP and NICHQ. Founded in the summer of 2003, UPIQ is a partnership among: (1) Intermountain Pediatric Society/Utah Chapter, American Academy of Pediatrics; (2) Department of Pediatrics, University of Utah; (3) Utah Department of Health's (UDOH) Division of Health Care Financing (Medicaid); (4) UDOH's Division of Community and Family Health Services; (5) Intermountain Health Care's Primary Care Programs; and (6) HealthInsight, a quality improvement organization serving Utah and Nevada. UPIQ has submitted several grant proposals for funding of learning collaboratives that will result in more pediatric practice teams working to develop QI processes within their practices to enhance developmental screenings, promote medical homes, and address early childhood mental health issues. Grants that have provided funding to UPIQ included a CATCH grant from the American Academy of Pediatrics and an ABCD II grant from the Commonwealth Fund. The Department also provides Title V funding to support this initiative. Most recently, CSHCN has committed funding to a new round of UPIQ medical home activities.

The Perinatal Mortality Review (PMR), SIDS and Utah PRAMS (Pregnancy Risk Assessment Monitoring System) programs are engaged in continuous efforts to monitor and improve the quality of care for women, mothers and infants in Utah. Both the PMR and SIDS programs utilize vital records and medical records data to track trends in infant deaths. PRAMS data are collected by surveying Utah mothers to determine trends and problems related to their pregnancy and birth experiences. All of these data will be utilized for planning interventions that are evidenced-based and therefore more effective public health strategies.

Another mechanism to monitor how effective Title V programs are addressing needs of these populations is through monitoring of the MCH performance measures. By annually reviewing progress with attainment of its established goals toward the performance measures, the state is able to determine which areas require more attention.

For injury prevention programs, evaluation is integrated with routine program operations. Evaluation will be practical and ongoing and will involve program staff and stakeholders. Activities will be evaluated on their merit, worth, and significance. Evaluation results will be reported to stakeholders. Data from the 11 core data sets will be used for long-term outcome evaluation. Ultimately the goal of injury prevention activities is to decrease morbidity and mortality, which will be evaluated through analysis of vital records, hospital discharge data, Fatality Analysis Reporting System, emergency department data, medical examiner and coroner data, child death review data, and the Uniform Crime Reporting System. The Behavioral Risk Factor Surveillance System, Youth Behavior Risk Survey, National Occupant Protection Use Survey, and emergency medical services data will be used for short-term impact evaluation to monitor behavior change.

Whenever possible, the Tobacco Prevention and Control Program acquires and disseminates recognized information regarding standards of care that contain a tobacco-related element. Agency for Health Care Policy Research guidelines for provider interaction with tobacco-

using patients is an example. The standards were developed at the national level but are promoted through state and local health care provider programs. Development of guidelines and protocols for various youth-related tobacco prevention activities also occurs at the state level. State-level data collection, e.g., compilation of data and reporting system for teen tobacco cessation programs, allows trainers to monitor effectiveness and make changes when warranted. Finally, collection and reporting of underage tobacco compliance checks, accessing Juvenile Court reports on youth tobacco-related offenses act to allow measurement of extent and nature of underage tobacco use at state and local levels.

The Tobacco Prevention and Control Program (TPCP) uses a variety of mechanisms to ensure quality improvement of its funded programs. In collaboration with an independent evaluation contractor, the TPCP conducts focus groups to plan anti-tobacco marketing messages and strategies; telephone surveys targeting youth, and smoking as well as non-smoking adults to assess tobacco use and the impact of the marketing campaign; and school surveys and key informant interviews with community partners and representatives of disparately affected populations to learn about tobacco use and tobacco-related concerns among specific target groups. The TPCP consistently evaluates trainings and presentations through end-of-session surveys. The findings of these data collection efforts are used to plan for program improvements. Additional measures to address quality improvement include site visits with local health departments, community mini-grant recipients, and recipients of community collaboration grants. Site visits help identify local community programming and training needs. They also increase collaboration between the TPCP and funded partners.

CSHCN manages a number of federal grants, as previously mentioned, such as ULEND, Utah Genetics Implementation, URADD (Utah Registry of Autism and Developmental Disabilities), EHDI, and Centers for Birth Defects Registry. As an award recipient, CSHCN programs participate in the specified federal Quality Assurance and Improvement guidelines and evaluation plans for each grant project.

CSHCN staff work closely with contracted local health department staff who provide locally based care coordination and who support the traveling clinic. Currently, CSHCN conducts local patient chart audits, and conducts yearly satisfaction surveys of families served through the satellite teams. Yearly training is conducted to maintain the knowledge base of contract staff. The monitoring of quality of care and maintenance of training is difficult, due to the distance between the sites and the CSHCN home office. In 2005, CSHCN staff will provide training and support to local health department staff in an initial quality improvement effort.

The Fostering Healthy Children Program (FHCP) serves the high-risk population of children with special health care needs for the children in Utah's foster care system. Program monitoring and ongoing quality improvement activities are critical to the provision of services to these children. Approximately 2200 children are in state custody at any one time during the year. Multiple foster home placements, difficulty in accessing health records, complex health care conditions, provider access in some areas of the state and a lack of foster parents who are trained to work with children with special needs are but a few of the problems these children face. This program ensures that the children in custody receive the required medical, dental and mental health services in addition to specialty medical services they need. State funding is maximized with federal Medicaid match funds to administer this program. FHCP staff assist DCFS staff in meeting the health needs of these children and youth by being co-located with DCFS case workers throughout the state.

Through contractual agreement, FHCP participates in two monitoring efforts for this population, which include annual Quality Case Review with the Child Welfare League of America as part of a Lawsuit Settlement Agreement and second, the State Office of Service Review which annually reviews documentation of services to children through a process called the Case Process Review. Additionally, FHCP in collaboration with their Advisory Board has developed and operationalized a child health acuity and needs assessment tool, the Health Status Outcome Measure (HSOM). This tool is utilized on an ongoing basis once the child enters foster care. It provides the ability for the staff to make sure the child is getting all of his/her needs met. The acuity tool continues to be updated as it is used to better track the ongoing needs for this vulnerable population.

FOUR CONSTRUCTS OF A SERVICE SYSTEM FOR CHILDREN WITH SPECIAL HEALTH CARE NEEDS

This section is only a small representation of how the state addresses the four constructs of a service system for children with special health care needs. Sections of the needs assessment include many citations about the work of the state to foster a service system for these children. Please refer to these sections for a more complete picture of Utah's efforts in this arena.

CSHCN works in collaboration with partners at state, community and private levels of health care provision to develop and expand existing resources for all Utah children. CSHCN and the University of Utah Department of Pediatrics collaborate to provide multidisciplinary services to children and families in rural Utah through CSHCN traveling clinics. Training efforts through the Utah Leadership Education in Neurodevelopmental Disabilities (ULEND) and Utah Medical Home grants work to support and expand the expertise of local private practitioners as they provide medical homes to CSHCN. Also, many of the trainees in the ULEND Program have the opportunity to participate in traveling and itinerant CSHCN clinics throughout the state and develop and appreciation (and hopefully a professional concern) for the difficulties encountered by rural families who do not have access to health care. Through the ULEND Program, collaborative partnerships are being developed to provide services, information, and educational support to families. Collaborative partnerships currently exist with CSHCN, the University of Utah School of Medicine, Utah State University Center for Persons with Disabilities, Primary Children's Medical Center, Shriners Orthopedic Hospital, and private providers. The BabyWatch/Early Intervention Task Force on Mental Health of Infants and Toddlers, an interagency task force which works to improve the early identification, prevention and treatment of children with mental illness and behavioral disorders, includes a diverse group of community early childhood practitioners, early intervention, state agencies, hospitals, pediatricians, obstetricians and advocates to complete a needs assessment, incorporating existing options for infant and toddler mental health.

The CSHCN Bureau, in collaboration with numerous other public and private entities, is working toward the six MCHB core components of: 1) family/professional partnership at all levels of decision-making; 2) access to comprehensive health and related services through the medical home; 3) early and continuous screening, evaluation and diagnosis; 4) adequate public and/or private financing of needed services; 5) organization of community services so that families can use them easily; and 6) successful transition to all aspects of adult heath care, work and independence. The Bureau has identified Utah's Medical Home initiative as the cornerstone of building a successful system that addresses all the components. The Utah Collaborative Medical Home Project is a collaborative effort with the University of Utah Department of Pediatrics, Utah State University, Medicaid and Utah Family Voices that provides outreach and support to medical

homes statewide for children with special health care needs (CSHCN) in primary care settings. Originally funded by an MCHB grant, the project is guided by a broad-based advisory committee, composed of private pediatric and family practice physicians, families, allied health professionals and other state partners, such as education, vocational rehabilitation and Medicaid.

At the heart of the six core components is family/professional partnerships at all levels of decision-making. However, meaningful sustained family/professional partnerships are challenging to establish and maintain. The challenges become even greater in establishing and maintaining family/professional partnerships when the family is not from the state's predominant culture. Providing families with information is critical to their success as partners in the decision-making for the children. In the 2000 Child Health Survey, families identified their need to meet and learn from other parents of CYSHCN.

Over the past 5 years, numerous successful public and private projects have expanded and improved the service system for Utah CYSHCN and families at both the state and community level. Despite significant changes and improvements in the system, gaps in services and needs remain as evidenced by data from surveys and reports from parents and providers. In March 2005, as part of the larger Title V Needs Assessment, the Bureau of Children with Special Health Care Needs worked with the CSHCN Subcommittee to review data from state and national surveys as well as the state Title V Key Informant Interview. Issues and needs were prioritized for the Bureau to address over the next five years. The top issues for Utah children and youth with special health care needs were: funding of health care, continued expansion of Medical Home, improvement of transition and vocational rehabilitation, provision of health care in rural Utah and ethnic and cultural health care delivery.

CSHCN has promoted the systematic integration of community-based services for CYSHCN and their families throughout Utah through either leadership or participation in a number of state, local, public/private projects. These projects include Medical Home; Autism Surveillance; Birth Defects Surveillance; Genetics Implementation Grant; the Child Health Advanced Record Management (CHARM) Initiative*;* itinerant multidisciplinary and specialty clinics throughout the rural areas of the state; collaboration with the Utah Leadership Education in Neurodevelopmental Disabilities Grant (ULEND); Early Hearing Detection and Intervention Grants; SSI outreach, information, and referral and transition to adulthood for youth with special needs.

Currently, the UDOH has developed a number of health care information systems, including: Newborn Screening, the Utah Statewide Immunization Information System, Newborn Hearing Screening (EHDI), Vital Statistics, Birth Defects, WIC, and is actively developing others (Baby-Watch / Early Intervention). Tighter integration among them, however, would improve service quality by allowing users of one system to have immediate access to information currently found in another. The CHARM (Child Health Advanced Record Management) Project is a concerted effort to share data among health-care systems in real-time. When complete, the shared data will provide a virtual health care record that will be called the Child Health Profile (CHP).

CSHCN Bureau collaborates with other Department programs through committees and advisory boards such as the Emergency Medical Services for Children Advisory Board, and the Child Fatality Review Committee (Is someone assigned to attend the quarterly meetings?). CSHCN Bureau provides consultation in the development of health care standards for programs that work with children with special health needs, such as the Violence and Injury Prevention Program, the Medicaid EPSDT Utilization Review Committee, and the Division of Child and Family Services Health Care Advisory Committee.

CSHCN Bureau participates in Senator Orrin Hatch's Advisory Committee on Disability Issues, a forum for national and state political issues affecting people with disabilities, provides direct input to Senator Hatch's office through conferences with his congressional aides. Through this committee the scope of involvement with other public and private agencies is significantly broadened to include the Disability Law Center, the ARC of Utah, School for the Deaf and Blind, Office of Rehabilitation, Governor's Council on People with Disabilities, University of Utah Medical Center Rehabilitation Services, Utah State University Disability Resource Center, and families of people with disabilities.

The chair of the Ethnic Health Advisory Committee is an active member of the MCH/CSHCN Advisory Committee and has been involved in the CSHCN needs assessment process. CSHCN has presented an overview of CSHCN programs to the Ethnic Health Advisory committee, and plans to return to the committee for consultation on specific health issues or program delivery. CSHCN also plans to work closely with the Division's Office of Multicultural Health to identify barriers to care for children with special health care needs in ethnic minority families. In addition, CSHCN will collaborate with Center for Persons with Disabilities at Utah State University, which has recently been funded to evaluate the needs of people with disabilities within the Utah Hispanic community. CSHCN already employs a social worker with specialized in outreach to Hispanic children with disabilities and their families.

State collaboration with other state agencies and private organizations

CSHCN works in collaboration with partners in state, community and private levels of health (medical, dental and mental health) care provision to develop and expand existing resources for all Utah children. CSHCN and the University of Utah Department of Pediatrics collaborate to provide multi-disciplinary services to children and families in rural Utah, through CSHCN traveling clinics. Training efforts through the new ULEND and Utah Medical Home grants work to support and expand the expertise of local private practitioners as they provide medical homes to CSHCN. Administrative CSHCN staff has been active in the Oral Health Coalition, which continues to identify barriers and to develop and implement strategies to improve access to dental services. Finally, CSHCN continues to work with the state Medicaid community mental health centers to improve the ability of mental health providers to evaluate and treat CSHCN and to improve the communication among mental health providers and primary and tertiary care providers about CSHCN.

In the 2000 CSHCN Child Health Survey, behavioral conditions such as attention deficit, hyperactivity disorder (ADHD,) were the most commonly identified condition for Utah CSHCN, with 35% having a behavioral condition. The CSHCN clinical programs coordinate with primary care providers and with community mental health centers for individual children throughout the state. Through the Health and Human Services Frontiers Mental Health Grant awarded to the state Division of Mental Health, multi-agency efforts have been underway to improve the capacity of the community mental health centers to provide diagnosis and intervention for children. A third example of collaboration with other state agencies around the mental health of children is the CSHCN efforts for children with mental health and behavioral conditions on the newly established BabyWatch Early Intervention Task Force on the Mental Health of Infants and Toddlers. This Task Force is an interagency group working to improve the early identification, prevention and treatment of children with mental illness and behavioral disorders. The task force includes a diverse group of community stakeholders including early childhood practitioners, early intervention, state agencies, hospitals, pediatricians, obstetricians and advocates to complete a needs assessment, incorporating

existing options for infant and toddler mental health. Three workgroups have been formed to address service delivery, training and research to practice to collect and analyze information to develop a strategic plan.

CSHCN Bureau works with Medicaid to administer the Travis C. Waiver, a home and community-based waiver currently serving 120 technology dependent children and their families. At this time, there are 45 children on the waiting list. CSHCN has established the capacity to provide contractual Administrative Case Management to children with special health care needs who are Medicaid eligible. CSHCN staff has also been involved in the development of a new Home and Community Based Waiver Program for children nearing the end of life. This waiver, if funded, will provide home-based services to 30 children in the first year. The CSHCN parent advocate coordinator participates on the UDOH Medicaid Advisory Committee.

CSHCN Bureau, Medicaid and Division of Child and Family Services (DCFS) in the Department of Human Services developed the Fostering Healthy Children Program (FHCP) to improve the health care of children in Utah's Foster Care system. FHCP is a collaborative effort between these two agencies, in which CSHCN Bureau nursing staff is co-located with DCFS caseworkers and assists them in coordinating the children's health care. Since all foster children in Utah are covered through Medicaid, the FHCP staff collaborates closely with Medicaid to ensure that services are accessible for this population of children with special needs.

The CSHCN Assistant Bureau Director serves as the Chairperson for the Health Care Consortium for the Division of Child and Family Services (DCFS), which meets bi-monthly and advises the DCFS Board on the health status issues for children in the child welfare system. The council identifies barriers and works toward the development of solutions to improve access and continuity of health care.

State support for communities

The Bureau continues to provide rural itinerant specialty clinics and supports the families and children served in these clinics with community case management teams through the local health departments in nine rural sites. Clinical follow up to traveling clinics is provided through Telehealth. Formal training for satellite teams is provided on-site, through Telehealth and once per year at the Salt Lake City CSHCN office. Local nursing case management is also provided by nurses who partner with local Department of Human Services office staff in eight Utah sites to provide health case management to children in foster care.

The Utah CSHCN Bureau is participating in the MCHB funded grant awarded to Utah State University/EIRI "Utah Clicks" project (previously Utah Electronic State Application System - UESAS) that has developed a web-based resource application system for families. CSHCN clinical programs and the Baby Watch Early Intervention Program are two of the five initial programs offering electronic applications to families statewide.

CSHCN Bureau staff has been active in providing technical assistance and consultation for a number of community development efforts. The BabyWatch/Early Intervention Program has initiated a training program for early childhood staff through state universities and remote campuses. The state program also provides training and certification of providers throughout Utah in an effort to increase the quality of early childhood education providers.

Fostering Healthy Children Program (FHCP) nurses provide education and training to foster parents and biological parents on health care needs of children in custody. FHCP nurses provide education and consultation to health care staff in the Salt Lake County Shelter, the Christmas Box House, Boys and Girls Group Homes. They also provide health care training to Human Service

caseworkers in local offices statewide. FHCP participates in Child and Family team meetings on medically fragile children who are in Utah's Foster Care system.

The Utah Medical Home Collaborative staff provides training and technical support to physician offices in providing medical homes for children. The Medical Home Collaborative supports the MedHome Portal website for physicians, families, educators and paraprofessional in accessing resources and diagnostic information; conducting monthly physician phone conferences on medical home topics of interest; publishing a quarterly newsletter; and, presenting at educator and family conferences. The Family Voices Coordinator provides training and support in the medical home offices.

CSHCN, Utah Family Voices (UFV) and the Utah Parent Information and Training Center (UPC) are collaborating on a Center for Medicare and Medicaid Services grant, which is designed to establish a Family-to-Family Center, to enhance community family-to-family activities and support development of a family database. Two Family Health Partners have been hired and trained to assist in family-to-family health information and education. Family Health Partners will provide consultation and involvement in development of materials for various family-to-family projects such as the Utah Collaborative Medical Home project, the ULEND project and medical residency training. A toll free information and referral line will be established and staffed by trained parents. The Family to Family grant, in collaboration with the Utah Collaborative Medical Home Project, will establish a statewide Family Advisory Committee which will include key community representatives such as families of children and youth with special health care needs, a young adult with special needs, key CSHCN Bureau staff, private providers and a representative from Medicaid.

Through an MCHB Financing Technical Assistance Initiative, Utah Family Voices will conduct parent focus groups to ascertain the health care insurance and funding issues facing families of CSHCN. The results will be used to develop a parent-focused tool kit for the MedHome Portal website, which is available to individuals and professionals in communities statewide.

Hearing, Speech and Vision Services (HSVS) Program continues to provide training, in-service and consultation statewide to Early Head Starts, Head Starts, Early Intervention and local health departments on hearing screening protocol, monitoring risk factors and follow up. Additionally, HSVS provides technical assistance, training and support on newborn hearing screening policy and protocol to hospital newborn nurseries statewide. The two rural-based HSVS audiologists have portable auditory brainstem response diagnostic equipment that is used in the rural areas of the state. This provision allows for accurate and timely assessment of newborns that do not pass hospital newborn hearing screening, and dramatically reduces financial and travel difficulties for families in remote areas.

The School Age and Specialty Services (SASS) Program addresses issues of transition, cultural effectiveness and access to Social Security and Medicaid, as well as providing school-based clinics for children and youth with special health care needs. Community-based CSHCN satellite site staff receives training, consultation, and support, particularly in the area of adolescent and young adult transition services. SASS collaborates with other private organizations (i.e., Shriners Hospital for Children) in presenting "transition fairs", where service providers can offer information on health care, Medicaid, SSI, independent living, vocational rehabilitation and then coordinates with the community-based programs to identify possible participants from their communities. SASS also collaborates with Shriners Hospital to take Shrine representatives to community orthopedic clinics to facilitate the referral of eligible children to their service.

Coordination of health components of community-based systems

CSHCN Bureau works with Primary Children's Medical Center (PCMC) charitable contributions to enhance the coverage of medical care for children with special needs. In 2004, PCMC tightened its eligibility guidelines, and coverage of children is not as liberal as in previous years. However, CSHCN and PCMC continue to collaborate on coverage of surgeries and treatments for children who have no other health care coverage options, such as adequate insurance, CHIP or Medicaid. CSHCN has been able to augment coverage for services on a limited number of children who have CHIP insurance, but whose treatment is not covered. The CSHCN Bureau provides financial and in-kind support to collaborative specialty clinics with University of Utah Health Sciences Center, Shriners Hospital for Children and PCMC. CSHCN Bureau staff supports the Utah Center for Assistive Technology in providing evaluations and adaptation of equipment for children.

The CSHCN BabyWatch/Early Intervention Task Force on Mental Health of Infants and Toddlers, an interagency task force which works to improve the early identification, prevention and treatment of children with mental illness and behavioral disorders, includes a diverse group of community early childhood practitioners, early intervention, state agencies, hospitals, pediatricians, obstetricians and advocates to complete a needs assessment, incorporating existing options for infant and toddler mental health.

CSHCN and MCH collaborate with the Utah Division of Substance Abuse and Mental Health through several meetings, which have been devoted to discussion about the ways the departments, can collaborate in a grant recently awarded the Mental Health Service System to improve Utah's Mental Health infrastructure, Utah's Transformation of Child and Adolescent Network (Utah CAN). The Bureau of CSHCN is collaborating with this effort especially through its Medical Home initiatives, including the MedHome Portal website.

The CSHCN Bureau Director has been involved in the development of several grant applications by Primary Children's Medical Center. Members of the Pediatric Ambulatory Care Committee, University of Utah, Department of Pediatrics have included CSHCN Bureau staff and other pediatric community providers in the development of a Robert Wood Johnson Foundation Asthma Grant and a CSHCN Ambulatory Care Grant. CSHCN has also helped to write or has supported the Department of Pediatrics application to the National Library of Congress grant to expand modules on the MedHome Portal website hosted by the University of Utah.

The CSHCN Bureau Director meets quarterly with the Primary Children's Medical Center Inpatient Rehabilitation Director to collaborate about children with chronic illness. Specifically, issues are addressed about children with special health care needs, such as traumatic brain injury (TBI), cerebral palsy, and transition from acute rehabilitation settings. The CHSCN Bureau Director also participates in Emergency Medical Services (EMS) for Children Advisory Board.

Coordination of health services with other services at community level

CSHCN staff uses their expertise to identify and weigh competing factors, which may limit the degree of accessibility or availability of services across the state. This work is done in conjunction with all the other community organizations and individuals who are interested in this effort. The MCH Advisory Committee and staff involvement in various other committees, such as the Early Childhood Council, Covering Kids Utah Project, etc. raise issues of service need for MCH populations. Staff evaluates need and work towards refocusing efforts and resources as appropriate and available.

The CSHCN Bureau Director hosts the Interagency Coordinating Council for the BabyWatch/Early Intervention Program. Membership of this council ensures a forum for

collaboration among all the organizations and agencies and families of preschool children in early intervention programs.

In 2004, the Utah legislature cut funding for the Family and Communities Together (FACT) initiative. This initiative had been successful in establishing statewide Interagency Consultation Teams, a state level team of professionals that facilitated problem resolution in collaboration with families, local community agencies, local interagency councils and local administrative teams in providing appropriate support to children and youth who have challenging needs. Although the full initiative is no longer supported by state funds, FACT Local Interagency Councils and Executive Interagency Coordinating Council continue to be active. CSHCN staff has helped to develop training materials for state agencies in the delivery of interagency collaborative, coordinated, family-centered services to families and children.

V. Selection of State Priority Needs

Needs Assessment Summary

Utah fares well related to the health of mothers and children with generally positive outcome measures and a health population overall. However, the health care system is currently not fully able to address the needs of some MCH populations, such as uninsured women, women (and children) who do not have documentation of citizenship, the growing populations of foreign-born and refugees, access to services, especially in the rural and frontier areas of the state. Utah was ranked 48th among the 50 states and District of Columbia for the number of "Child Health MDs" per 100,000 children (55.7 vs. the national average of 85) and 40th for general pediatricians (40 vs. 57.5) per 100,000. The same trend is noted for obstetricians and gynecologists in the state. There are vast areas of the state without any specialty provider.

Utah's population is unique in that we have the highest birth rate in the nation, and a much higher proportion of children in the state population compared to national population distributions. More than 30% of Utah's population is children 17 and under (32.2%) compared to national at 25.7%. Adults between the ages of 18 and 24 years of age comprise 12.8% of Utah's population compared to national at 9.1%. This disproportionate age distribution poses challenges to numerous systems in the state: health care, schools, etc. The percent of Utah family households with children is 30% higher than the rest of the nation, 42.0% versus 32.2%. Medicaid paid for 31.6% of all Utah deliveries in 2003, with 40% enrollment among the infants born that year.

Utah has ranked 49th in the nation in the percent of mothers receiving adequate prenatal care for the past several years. Over one quarter of Utah women who recently delivered a live born infant report moderate to severe postpartum depression. A recent comparison of national PRAMS data showed that Utah had the highest rate of reported postpartum depression among the seven states reporting the measure. A recent analysis of PRAMS data from nineteen states, conducted by CDC, found that Utah had one of the highest rates of early infant discharge coupled with the highest rate of no infant follow up within the first week of discharge.

The 2003 Health Status Survey indicated that 8.8% of children were unable to get needed medical, dental, or mental health care in the previous 12 months, and that 28.1% of children had no regular medical checkup. Approximately 10% of Utah parents reported that their child had no "usual provider" or that they rely on the emergency room for health care. Children and youth with special health care needs who were more likely to be without health insurance coverage included children age 6 to 11 years (8.1%) and children living in households with incomes below the federal poverty level (19.9%). This finding is especially concerning, since in Utah almost all uninsured children living below 200% of the federal poverty level are eligible for Medicaid or the Children's Health Insurance Program (CHIP). More than 23,500 young adults in Utah with disabilities will need transition to adult health care and access to multiple services to allow them to live as independently as possible**.**

According to the 2003 Youth Risk Behavior Survey, 7% Utah students were overweight and 11.3% were at risk for overweight, a steadily increasing number following the national trends of 13.5% and 15.4% respectively. Almost 27% of Utah students reported that they had felt so sad or hopeless almost every day for two weeks or more in a row that they stopped doing some usual activities. Suicide is the second leading cause of death among Utah residents 1-19 years.

Utah has an11.0% prevalence of CYSHCN. Overall, 9% of children with special health care needs were reported with "fair" or "poor" health. Fifty-nine percent of CSHCN had one or more days out of the last 30 when their physical health was "not good" (including illness and injury). On

average, CSHCN experienced 3.9 sick days in the last month before the survey. Approximately 42% of CSHCN were reported to have one or more days in which their mental health was "not good" (including stress, depression, and emotional problems). On average, CSHCN experienced 4.2 poor mental health days in the last month.

Utah does face a number of health care system challenges. The rate of uninsured has increased over the past two years, which is very concerning to the Governor and public health officials. Utah's Medicaid eligibility for pregnant women and infants remains at 133% FPL and also includes an asset test for pregnant women and children for eligibility determination, which leaves out the "working poor" from coverage under this program. The State CHIP Program, separate from Medicaid, has been challenged with higher demand for coverage than the budget would allow, forcing the program to cap enrollment. Fortunately the 2005 Legislature appropriated additional state funding that will allow another 12,000 children to be enrolled. Children with special health care needs continue to place increasing demands on state dollars in an attempt to meet the needs of the children and youth and their families. Early Intervention has had to restrict enrollment to children with developmental delays, taxing that system and its budget each year. Other CSHCN programs have had to modify eligibility criteria or services provided to stay within their budgets.

On a positive note, Utah has developed or participated in some innovative programs, strategies, collaborations, and data linkage projects that have been recognized nationally. These include the CSHCN Medical Home Project, Utah Pediatric Partnership to Improve Healthcare Quality (UPIQ), CHARM (Child Health Advance Records Management System), Indicator Based Information System (IBIS), and so on.

Utah has strong relationships with many key partners, including Medicaid, which enables the State Title V agency accomplish its work more efficiently and effectively than if we were operating alone. Utah has been known nationally for it creative, innovative, financing with Medicaid to support administrative, consultative and outreach efforts on behalf of Medicaid participants and the Medicaid program. Both divisions work closely together, with each providing to the other. For example, the Division of Community and Family Health Services provides clinical expertise for review of health plan services to mothers, children, and children with special health care needs. Medicaid participates with us on a number of advisory committees, thus providing us with a Medicaid perspective for our work.

As for specific health care priorities, Utah is beginning to grapple with the problems associated with overweight and obesity and mental health. The Department will sponsor an obesity summit in August 2005 to draw attention to the obesity problem in the state and increase awareness of the health and economic consequences of obesity. The mental health area is one in which we are just embarking on, which in part relates to the state department organizational structure, with the Department of Human Services having oversight of the mental health service system. The Utah Department of Health has now initiated efforts into mental health for mothers and children by hiring a Children's Mental Health Promotion Specialist who is a licensed clinical social worker with extensive experience in the field. Her efforts will be coordinated with others in the state, especially with the Department of Humans Services mental health infrastructure grant for children and adolescent mental health needs.

Priority needs

The top five issues for each area of the key informant survey identified by respondents are as follows:

Health Issues for Mothers and Newborn Babies
Unplanned pregnancies
Obesity
Depression or other mental health problems
Closely spaced pregnancies
Poor nutrition during pregnancy

Health Issues for Children and Adolescents
Lack of physical activity
Obesity
After school supervision
Teen pregnancy
Depression or other mental health problems

Health Issues for Children and Youth with Special Health Care Needs
Lack of physical activity
Lack of respite care
Depression or other mental health problems
Transition to adult life and self-sufficiency
Lack of child care

Health Care Services Issues
Dental insurance
Obtaining financial help for health care
Health insurance
Services not covered by insurance
Dental care

These results were presented to the members of the MCH/CSHCN Advisory Committee in a February meeting for their review. MCH/CSHCN Advisory Committee and subcommittee membership includes broad representation from local health departments, community health centers, the dental and medical provider community, nursing, Head Start, Child Care Licensing, Medicaid, Utah CHIP, the Utah Statewide Immunization Information System, Planned Parenthood Association of Utah, Family Voices, etc. as well as staff from other Department programs. The MCH/CSHCN Advisory Committee is comprised of three subcommittees, one for each of the three MCH populations. After the MCH/CSHCN Advisory Committee meeting, subcommittees met separately to discuss the survey results in more detail and after review of additional data, determined two to three priorities they recommended be addressed in the next five years.

State MCH/CSHCN Priorities for FY06-FY10

The MCH Advisory Committee met to review and comment on the issues that were highest in each area surveyed. Subcommittees of the Advisory Committee reviewed the survey results,

reviewed additional data on the health of each population as well as system challenges and made recommendations to the Title V leadership for consideration as state priorities.

Key Title V staff, including the Division's family advocate, reviewed the results of the survey and the subcommittee recommendations to identify finalize the state priorities and state performance and outcome measures

1. Depression and mental health (mothers, children)
2. Obesity (women [pre-pregnant and weight gain in pregnancy], children)
3. Intendedness of pregnancy (includes short interpregnancy spacing)
4. Medical home (all)
5. Access to health care for women of childbearing ages and children
    a. Women of childbearing ages who do not have insurance
    b. Rural health
6. Oral health (all)
7. Transition and vocational rehabilitation (CSHCN)
8. Ethnic/cultural
9. Genomics

State Performance Measures FY06-FY10

Key Title V staff, including the Division's family advocate developed state performance measures related to the new state priorities. We retained three of the previous state Performance Measures and developed six new Performance Measures to reflect the State Priorities. We decided not to develop State Performance Measures for ethnic/cultural or genomics as we want to work with those areas more to determine if we can develop an appropriate State Performance Measure. New performance measures are indicated with (N) in front of them:

(N) Percent of women of reproductive age (18-44) who is uninsured

Proportion of pregnancies that result in a live birth that are intended

(N) Percent of women with normal pre-pregnancy weight who deliver a live born infant

(N) Percent of women with appropriate pregnancy weight gain who deliver a live born infant

(N) Proportion of women who deliver a live born infant reporting moderate to severe depression who seek help from a doctor or other health care worker

(N) Percent of children who are at-risk for overweight and overweight

(N) Percent of youth during the last 12 months who feel so sad or hopeless almost every day for two weeks or more in a row that they stopped doing usual activities.

Percent of children six through nine years of age enrolled in Medicaid receiving a dental visit in the past year.

Percent of children with special health care needs in the rural areas of the state receiving direct clinical services through the state CSHCN programs.

Key Title V staff participated in an abbreviated version of CAST-5 to evaluate the state Title V agency's capacity. The Title V Director, MCH and CSHCN Bureau Directors along with other key staff reviewed the elements of CAST-5 to assess the Utah Title V agency's capacity needs. Overall the review indicates that Utah's Title V agency has much capacity and the elements that were noted as needing improvement really only reflect the desire to development these elements to a higher level. The elements are in place, but barriers may prevent staff from accomplishing as much as they would like. Overall, the agency has capacity for 21 of the 28 elements, with the remaining 7 elements needing improvement or further development. The seven elements included:

- Authority and funding sufficient for functioning at the desired level of performance – the challenges in this element include: inability to create new positions to address capacity needs due to legislative restrictions; restrictions on applying for grant funds if new positions are needed to carryout the grant; and limited state funds for grants that require non-federal match.
- Mechanisms for accountability and quality improvement – we have informal processes in place for quality improvement for many programs, but limited ability to implement quality improvement with contractors, such as local health departments. Programs providing direct services tend not to be receptive to quality improvement as it interferes with service provision.
- Formal protocols and guidance for all aspects of assessment, planning and evaluation cycle – this element is one that we need to focus more on and develop staff capacity.
- Adequate data infrastructure – We have strong data support, but capacity needs to be built to better support data needs of the state Title V agency in its work
- Other relevant state agencies – While the UDOH has strong collaborative relationships with many state agencies, the State Office of Education has been very difficult to engage in collaborative initiatives. With a new Executive Director, perhaps this will change for the better.
- Businesses – this is an area that the Division of Community and Family Health has embarked on to a certain degree, but needs further development.
- Ability to influence policy-making process – The Department has the ability to influence policymakers to the degree that is within the boundaries of state government roles and the Governor's agenda. The new Executive Director of the Department of Health has vast experience in government nationally which will greatly benefit public health and Title V in the state as he works to overcome challenges we face.

In addition to these processes that were developed specifically for the five year needs assessment process, the MCH Bureau sponsored meetings in 2004 with members of the State Perinatal Taskforce to identify four priorities to work on over the next year or so. Of all the issues included in the evaluation, four priority areas emerged:

Family planning
Low birth weight and prematurity
Barriers to prenatal care

Depression and other mental health issues

These four priorities correspond to the issues identified through the key informant survey. Members of the Taskforce have signed up for one of the four subcommittees to address each of the priorities. The subcommittees are developing strategies to address each of the priority areas.

The needs assessment process also included a review of status on National and State Performance and Outcome Measures, as well as Health Status, Health Systems Indicators and health care systems in the state. This review assisted in identifying priority areas along with the top issues obtained from the key informant survey. The needs assessment process also included a review of status on National and State Performance and Outcome Measures, as well as Health Status, Health Systems Indicators and health care systems in the state. This review assisted in identifying priority areas along with the top issues obtained from the key informant survey. The state accomplished 11 National Performance Measures. The Measures that we did not accomplish included several that we had made progress on, but the indicator was slightly lower than the objective. The areas that we did not achieve included: up-to-date immunizations for children, deaths of children due to motor vehicle accidents and youth suicides, uninsured children, low birth weight, very low birth weight infants born in tertiary centers, and entry into prenatal care. The measures for immunizations and uninsured children are 2004 data, however, the vital records data are provisional, which may impact the number of National Performance Measures obtained. State Performance Measures were all noted as accomplished, however, as with the National Performance Measures, some are reported with provisional data, so this too may change what was accomplished or not.

VI. Health Status Indicators

In reviewing the Health Status Indicators, all data for 2004 are provisional and thus reflect 2003 data. We expect that the low birth weight and related indicators will increase since the trend in low birth weight is increasing. We are hopeful that the trend in injuries will decline from 2003. Chlamydia rates will probably increase due to better more efficient testing methods that probably result in screening more teens with past traditional methods of testing that involved a physical examination. See Health Status Indicator Narrative for more thorough discussion of the HSIs.

VII. Outcome Indicators

Review of outcome indicators revealed that overall Utah is faring well related to mortality for children. Infant mortality fell to a rate of 5 per 1000 live births, the second lowest rate for the state in the past several years. The Black infant to white infant death ratio has increased (3.5 in 2003) in the past several years, a concern to public health officials. The Title V agency will need to review these deaths to determine strategies for future prevention. Neonatal mortality is at 3.6 per 1000 live births, a rate that has varied over the past several years. Postneonatal mortality has dropped to 3.6 per 1000 live births, perhaps a reflection of promotion of safety issues for young infants. We have seen a steady drop in perinatal mortality over the past couple of years. The child death rate decreased in 2003 which was welcomed given the increase noted in 2002. While Utah does fare relatively well compared with other states in perinatal, infant and child mortality, we continue to monitor individual death cases for identification of preventable factors to promote to reduce future deaths.

The State Outcome Measure is maternal mortality which we will continue to maintain as the Utah State Outcome Measure. The rate of maternal deaths has increased since 2002, which may reflect better case finding. For the purposes of the MCH Block Grant, we report maternal mortality

differently than is reported to NCHS. We use the expanded definition of maternal mortality to 12 months after the end of any pregnancy. We also link death certificates of women of childbearing ages to birth and fetal death records to identify as many women as possible for mortality review, thus providing us with more cases than are reported via death certificate data only. Each case is reviewed by a panel of experts to determine the role, if any, of the pregnancy with the woman's death.

Utah Dental Care HPSAs by County and Type of HPSA

- Full County Geographic HPSA
- Partial County Geographic HPSA
- Full County Low-Income HPSA
- Partial County Low-income HPSA
- Undesignated

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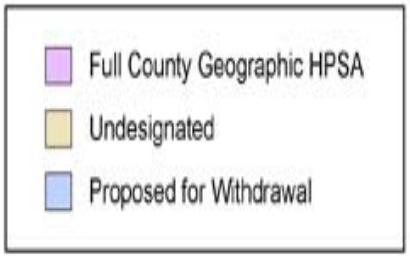
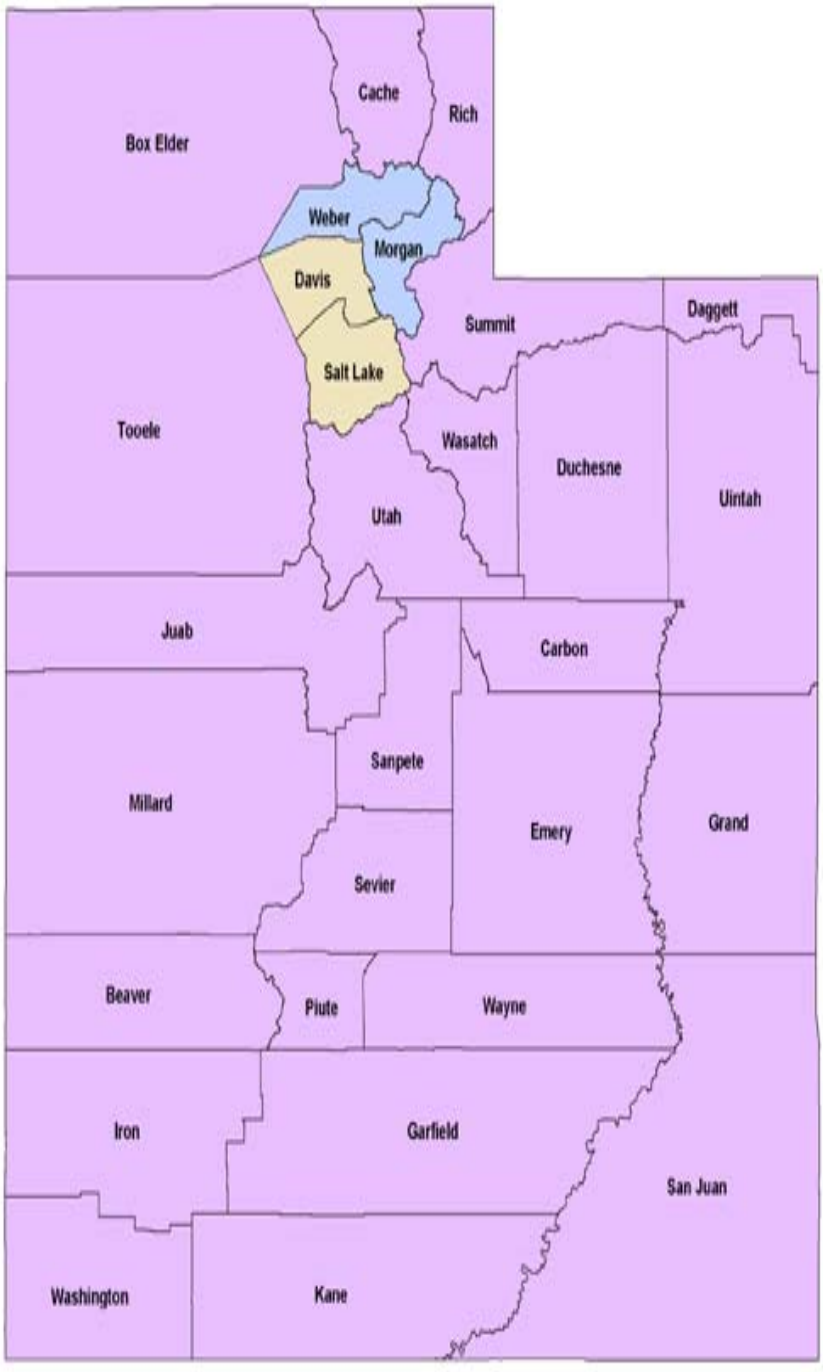
Updated: March 14, 2005

Utah Mental Health Care HPSAs by County and Type of HPSA





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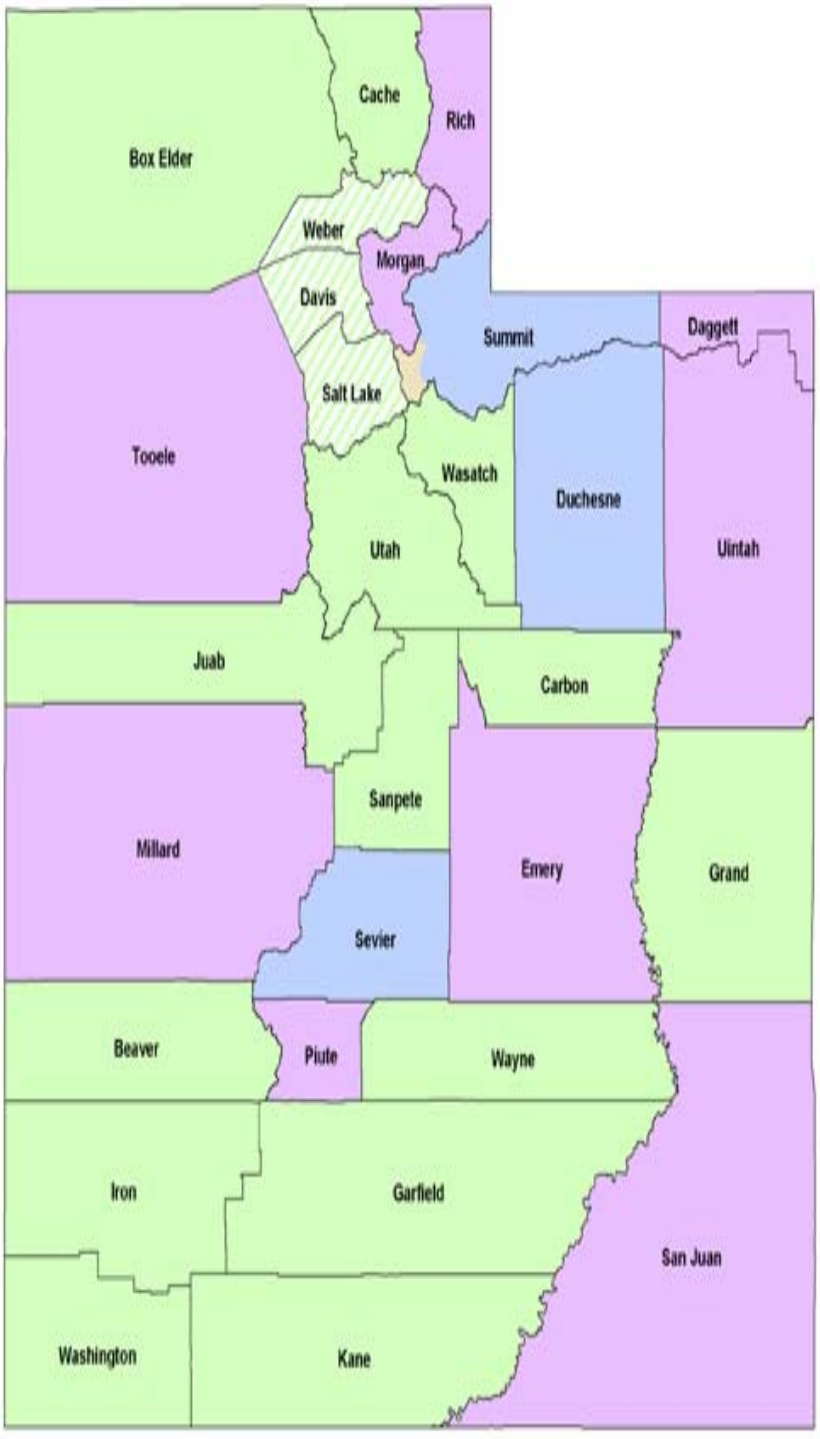
Utah Primary Care HPSAs by County and Type of HPSA

- Full County Geographic HPSA
- Full County Low-Income HPSA
- Partial County Low-income HPSA
- Undesignated Partial County
- Proposed for Withdrawal



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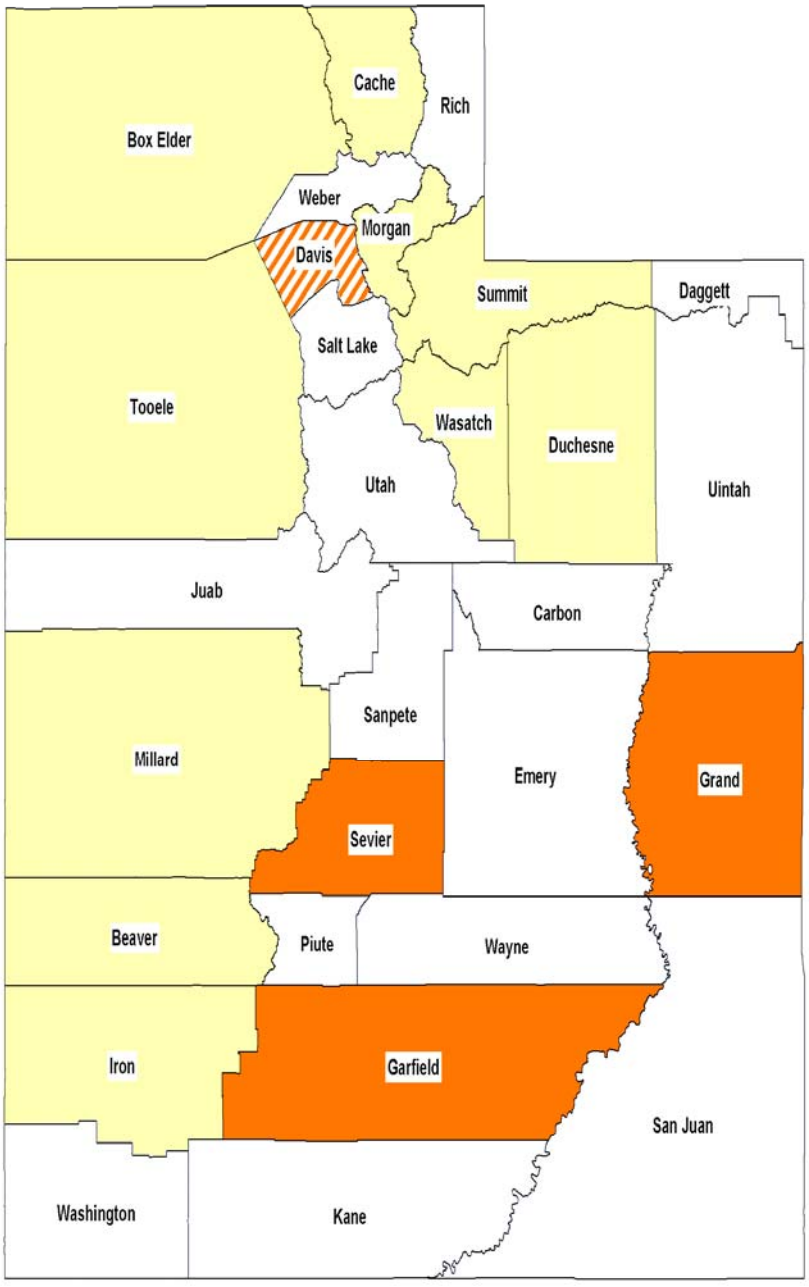
Updated: March 14, 2005

Utah Medically Underserved Areas and Medically Underserved Populations

- Full County MUA
- Partial County MUA
- Full County MUP
- Partial County MUP
- Undesignated Counties



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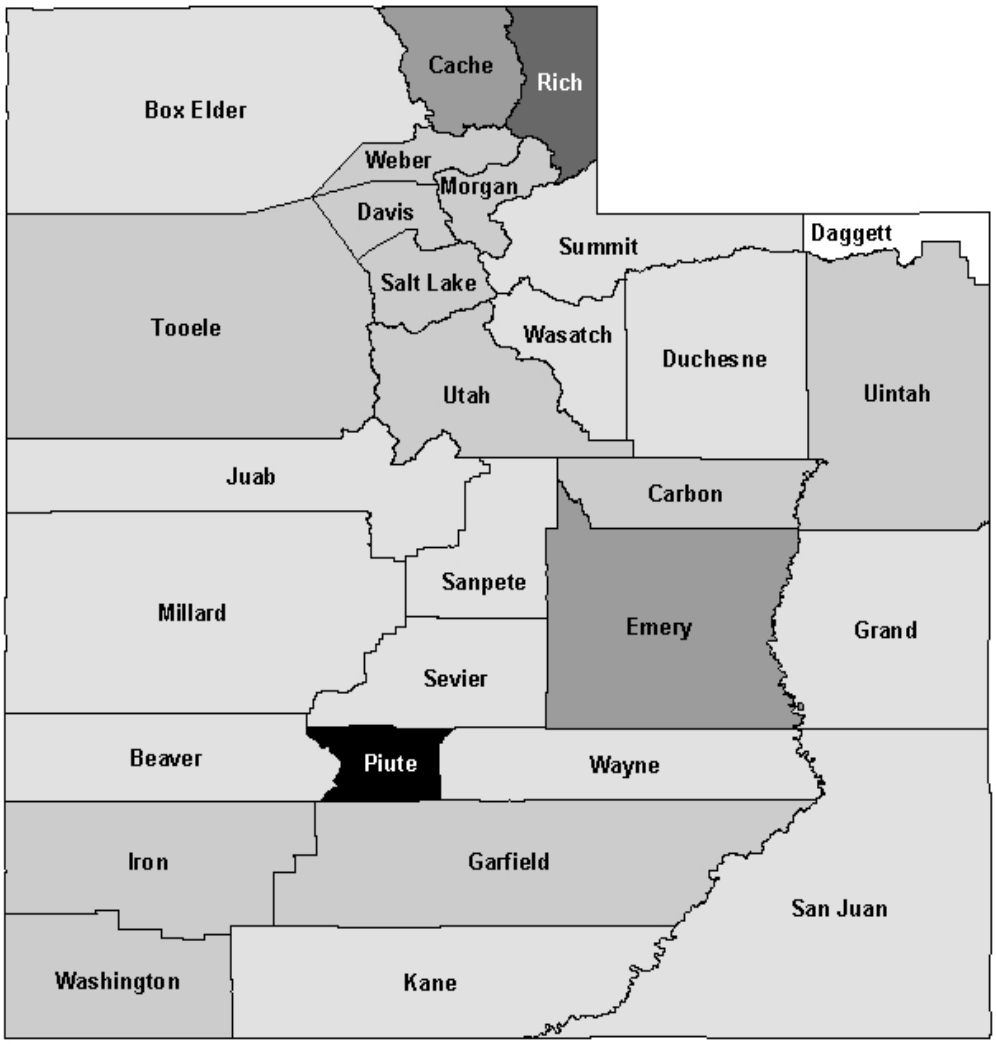
Updated: March 14, 2005

Population-to-Provider Ratios for Family Practice Physicians in Utah

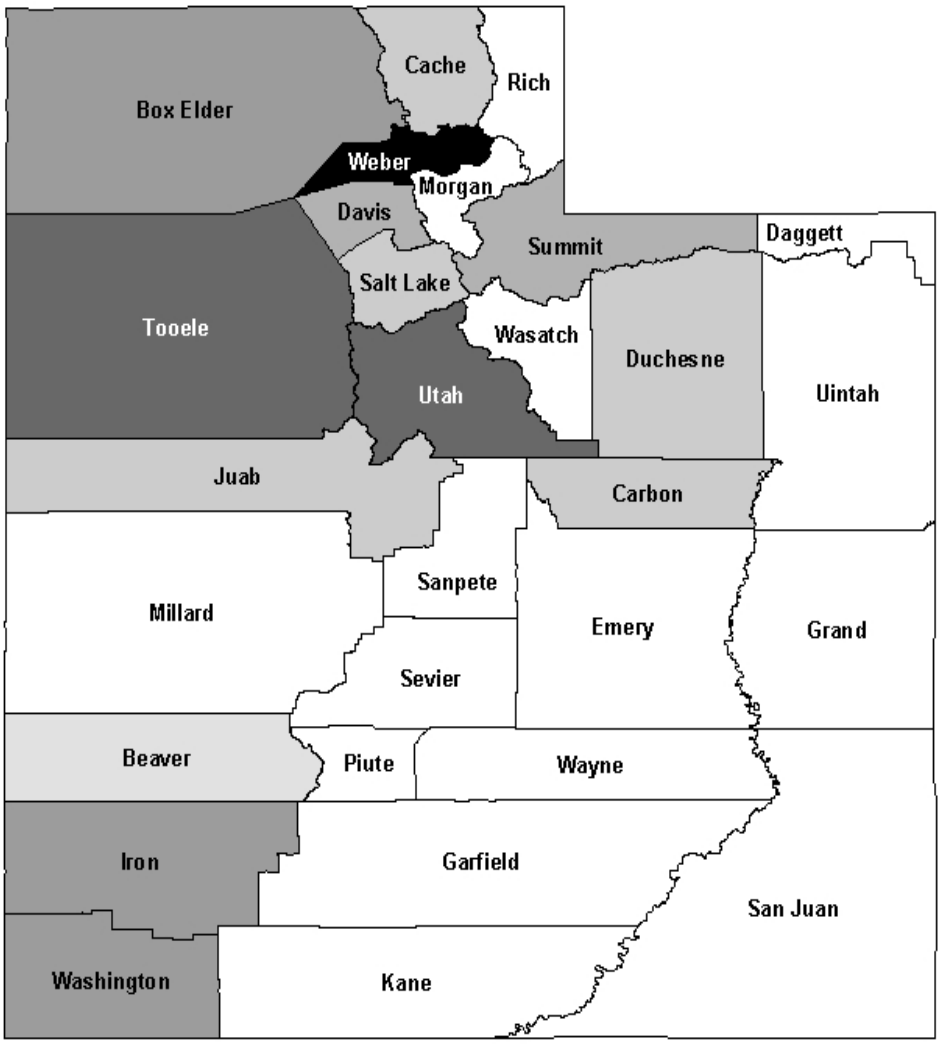


- None
- 1 - 4,000
- 4,001 - 8,000
- 8,001 - 12,000
- 12,001 - 16,000
- 16,000 - 20,000
- > 20,000

The number of physicians is based on the total number of physicians who are in family or general practice as counted in Health Professional Shortage Area surveys conducted between 2000 and 2004. Ratios are computed as follows: Resident-civilian Population / Number of Physicians. Resident-civilian population is calculated by subtracting the number of institutionalized population from the total population. The population totals used are from the U.S. Census Bureau (Census 2000, Summary File 1, 2000 data), or from Claritas (1998 - 1999 data).

Office of Primary Care & Rural Health, Utah Department of Health February 2005

Population-to-Provider Ratios for Internal Medicine Physicians in Utah



- None
- 1 - 6,000
- 6,001 - 12,000
- 12,001 - 18,000
- 18,001 - 24,000
- > 24,000

The number of physicians is based on the total number of internal medicine physicians who provide primary care for patients as counted in Health Professional Shortage Area surveys conducted between 2000 and 2004. Ratios are computed as follows: Resident-civilian Population / Number of Physicians. Resident-civilian population is calculated by subtracting the number of institutionalized population from the total population. The population totals used are from the U.S. Census Bureau (Census 2000, Summary File 1, 2000 data), or from Claritas (1998 - 1999 data).

Office of Primary Care & Rural Health, Utah Department of Health February 2005

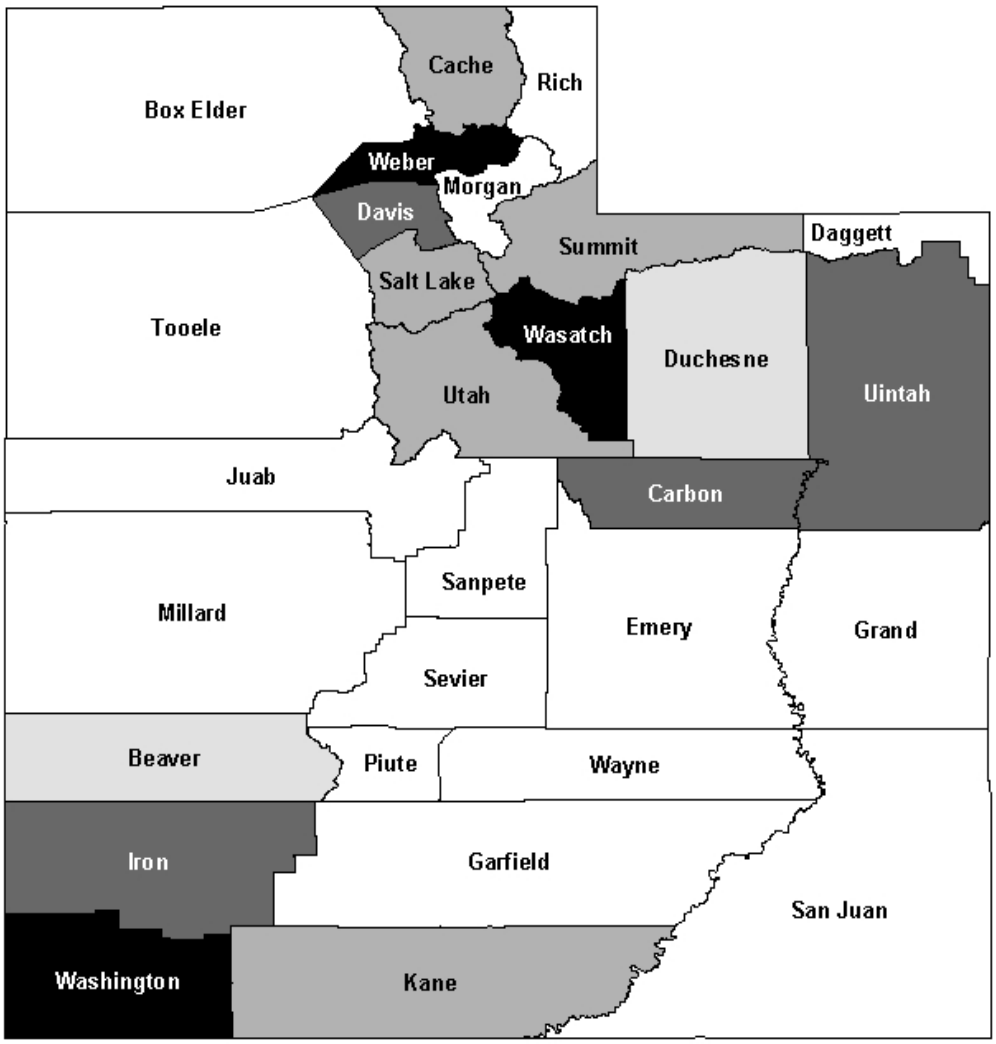
Population-to-Provider Ratios for OB/GYN Physicians in Utah

- None
- 1 - 2,500
- 2,501 - 5,000
- 5,001 - 7,500
- 7,501 - 10,000
- 10,001 - 12,000

The number of physicians is based on the total number of OB/GYN physicians who provide primary care for patients as counted in Health Professional Shortage Area surveys conducted between 2000 and 2004. Ratios are computed as follows: Female Population / Number of OB/GYN Physicians. The female population is the number of females ranging from 15 to 44 years of age in 2000. The population data is from the U.S. Census Bureau (Census 2000, Summary File 1, 2000 data).

Office of Primary Care & Rural Health, Utah Department of Health — February 2005

Population-to-Provider Ratios for Pediatric Physicians in Utah



- None
- 1 - 2,000
- 2,001 - 4,000
- 4,001 - 6,000
- 6,001 - 8,000

The number of physicians is based on the total number of pediatric physicians who provide primary care for patients as counted in Health Professional Shortage Area surveys conducted between 2000 and 2004. Ratios are computed as follows: Child Population / Number of Pediatricians. The child population is the number of children ranging from 0 to 17 years of age in 2000. The population data is from the U.S. Census Bureau (Census 2000, Summary File 1, 2000 data).

Office of Primary Care & Rural Health, Utah Department of Health February 2005